

106TH CONGRESS
2D SESSION

H. R. 4365

To amend the Public Health Service Act with respect to children’s health.

IN THE HOUSE OF REPRESENTATIVES

MAY 3, 2000

Mr. BILIRAKIS (for himself and Mr. BROWN of Ohio) introduced the following bill; which was referred to the Committee on Commerce

A BILL

To amend the Public Health Service Act with respect to children’s health.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Children’s Health Act
5 of 2000”.

6 **SEC. 2. TABLE OF CONTENTS.**

7 The table of contents for this Act is as follows:

Sec. 1. Short title.

Sec. 2. Table of contents.

TITLE I—AUTISM

Subtitle A—Surveillance and Research Regarding Prevalence and Pattern of
Autism

Sec. 101. Short title.

Sec. 102. Surveillance and research programs; clearinghouse; advisory committee.

Subtitle B—Expansion, Intensification, and Coordination of Autism Activities of National Institutes of Health

Sec. 111. Short title.

Sec. 112. Expansion, intensification, and coordination; information and education; interagency coordinating committee.

TITLE II—RESEARCH AND DEVELOPMENT REGARDING FRAGILE X

Sec. 201. Short title.

Sec. 202. National Institute of Child Health and Human Development; research on fragile X.

Sec. 203. National Institute of Child Health and Human Development; loan repayment program regarding research on fragile X.

TITLE III—JUVENILE ARTHRITIS AND RELATED CONDITIONS

Sec. 301. National Institute of Arthritis and Musculoskeletal and Skin Diseases; research on juvenile arthritis and related conditions.

Sec. 302. Information clearinghouse.

TITLE IV—REDUCING BURDEN OF DIABETES AMONG CHILDREN AND YOUTH

Sec. 401. Programs of Centers for Disease Control and Prevention.

Sec. 402. Programs of National Institutes of Health.

TITLE V—ASTHMA TREATMENT SERVICES FOR CHILDREN

Sec. 501. Short title.

Subtitle A—Treatment Services

Sec. 511. Grants for children's asthma relief.

Sec. 512. Technical and conforming amendments.

Subtitle B—Prevention Activities

Sec. 521. Preventive health and health services block grant; systems for reducing asthma-related illnesses through urban cockroach management.

Subtitle C—Coordination of Federal Activities

Sec. 531. Coordination through National Institutes of Health.

Subtitle D—Compilation of Data

Sec. 541. Compilation of data by Centers for Disease Control and Prevention.

TITLE VI—BIRTH DEFECTS PREVENTION ACTIVITIES

Subtitle A—Folic Acid Promotion

Sec. 601. Short title.

Sec. 602. Program regarding effects of folic acid in prevention of birth defects.

Subtitle B—National Center on Birth Defects and Developmental Disabilities

Sec. 611. National Center on Birth Defects and Developmental Disabilities.

TITLE VII—EARLY DETECTION, DIAGNOSIS, AND TREATMENT
REGARDING HEARING LOSS IN INFANTS

Sec. 701. Short title.

Sec. 702. Purposes.

Sec. 703. Programs of Health Resources and Services Administration, Centers for Disease Control and Prevention, and National Institutes of Health.

TITLE VIII—CHILDREN AND EPILEPSY

Sec. 801. National public health campaign on epilepsy; seizure disorder demonstration projects in medically underserved areas.

TITLE IX—SAFE MOTHERHOOD; INFANT HEALTH PROMOTION

Subtitle A—Safe Motherhood Monitoring and Prevention Research

Sec. 901. Short title.

Sec. 902. Monitoring; prevention research and other activities.

Subtitle B—Pregnant Mothers and Infants Health Promotion

Sec. 911. Short title.

Sec. 912. Programs regarding prenatal and postnatal health.

TITLE X—REVISION AND EXTENSION OF CERTAIN PROGRAMS

Subtitle A—Pediatric Research Initiative

Sec. 1001. Short title.

Sec. 1002. Establishment of pediatric research initiative.

Sec. 1003. Investment in tomorrow's pediatric researchers.

Subtitle B—Other Programs

Sec. 1011. Childhood immunizations.

Sec. 1012. Screenings, referrals, and education regarding lead poisoning.

TITLE XI—CHILDHOOD SKELETAL MALIGNANCIES

Sec. 1101. Programs of Centers for Disease Control and Prevention and National Institutes of Health.

TITLE XII—ADOPTION AWARENESS

Subtitle A—Infant Adoption Awareness

Sec. 1201. Short title.

Sec. 1202. Grants regarding infant adoption awareness.

Subtitle B—Special Needs Adoption Awareness

Sec. 1211. Short title.

Sec. 1212. Special needs adoption programs; public awareness campaign and other activities.

TITLE XIII—TRAUMATIC BRAIN INJURY

- Sec. 1301. Short title.
- Sec. 1302. Programs of Centers for Disease Control and Prevention.
- Sec. 1303. Programs of National Institutes of Health.
- Sec. 1304. Programs of Health Resources and Services Administration.

TITLE XIV—PREVENTION AND CONTROL OF INJURIES

- Sec. 1401. Authorization of Appropriations for programs of Centers for Disease Control and Prevention.

TITLE XV—HEALTHY START INITIATIVE

- Sec. 1501. Short title.
- Sec. 1502. Continuation of healthy start program.

TITLE XVI—ORAL HEALTH PROMOTION AND DISEASE PREVENTION

- Sec. 1601. Oral health promotion and disease prevention.

TITLE XVII—VACCINE COMPENSATION PROGRAM

- Sec. 1701. Short title.
- Sec. 1702. Content of petitions.

TITLE XVIII—HEPATITIS C

- Sec. 1801. Short title.
- Sec. 1802. Surveillance and education regarding hepatitis C.

TITLE XIX—NIH INITIATIVE ON AUTOIMMUNE DISEASES

- Sec. 1901. Short title.
- Sec. 1902. Juvenile diabetes, juvenile arthritis, lupus, multiple sclerosis, and other autoimmune-diseases; initiative through Director of National Institutes of Health.

TITLE XX—GRADUATE MEDICAL EDUCATION PROGRAMS IN CHILDREN'S HOSPITALS

- Sec. 2001. Extension of authorization of appropriations.

TITLE XXI—SPECIAL NEEDS OF CHILDREN REGARDING ORGAN TRANSPLANTATION

- Sec. 2101. Short title.
- Sec. 2102. Organ Procurement and Transplantation Network; amendments regarding needs of children.

TITLE XXII—MISCELLANEOUS PROVISIONS

- Sec. 2201. Report regarding research on rare diseases in children.

TITLE XXIII—EFFECTIVE DATE

- Sec. 2301. Effective date.

1 **TITLE I—AUTISM**
2 **Subtitle A—Surveillance and Re-**
3 **search Regarding Prevalence**
4 **and Pattern of Autism**

5 **SEC. 101. SHORT TITLE.**

6 This subtitle may be cited as the “Autism Statistics,
7 Surveillance, Research, and Epidemiology Act of 2000
8 (ASSURE)”.

9 **SEC. 102. SURVEILLANCE AND RESEARCH PROGRAMS;**
10 **CLEARINGHOUSE; ADVISORY COMMITTEE.**

11 Part B of title III of the Public Health Service Act
12 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
13 tion 317G the following section:

14 “SURVEILLANCE AND RESEARCH REGARDING AUTISM
15 AND PERVASIVE DEVELOPMENTAL DISORDERS

16 “SEC. 317H. (a) IN GENERAL.—The Secretary , act-
17 ing through the Director of the Centers for Disease Con-
18 trol and Prevention, may make awards of grants and coop-
19 erative agreements for the collection, analysis, and report-
20 ing of data on autism and pervasive developmental dis-
21 orders. An entity may receive such an award only if the
22 entity is a public or nonprofit private entity “(including
23 health departments of States and political subdivisions of
24 States, and including universities and other educational

1 entities). In making such awards, the Secretary may pro-
2 vide direct technical assistance in lieu of cash.

3 “(b) CENTERS OF EXCELLENCE IN AUTISM AND
4 PERVASIVE DEVELOPMENTAL DISORDERS EPIDEMI-
5 OLOGY.—

6 “(1) IN GENERAL.—The Secretary, acting
7 through the Director of the Centers for Disease
8 Control and Prevention, shall (subject to the extent
9 of amounts made available in appropriations Acts)
10 establish not less than three, and not more than five,
11 regional centers of excellence in autism and perva-
12 sive developmental disorders epidemiology for the
13 purpose of collecting and analyzing information on
14 the number, incidence, correlates, and causes of au-
15 tism and related developmental disorders.

16 “(2) RECIPIENTS OF AWARDS FOR ESTABLISH-
17 MENT OF CENTERS.—Centers under paragraph (1)
18 shall be established and operated through the award
19 of grants or cooperative agreements to public or
20 nonprofit private entities that conduct research, in-
21 cluding health departments of States and political
22 subdivisions of States, and including universities and
23 other educational entities.

24 “(3) CERTAIN REQUIREMENTS.—An award for
25 a center under paragraph (1) may be made only if

1 the entity involved submits to the Secretary an ap-
2 plication containing such agreements and informa-
3 tion as the Secretary may require, including an
4 agreement that the center involved will operate in
5 accordance with the following:

6 “(A) The center will collect, analyze, and
7 report autism and pervasive developmental dis-
8 orders data according to guidelines prescribed
9 by the Director, after consultation with relevant
10 State and local public health officials, private
11 sector developmental disorder researchers, and
12 advocates for those with developmental dis-
13 orders;

14 “(B) The center will assist with the devel-
15 opment and coordination of State autism and
16 pervasive developmental disorders surveillance
17 efforts within a region;

18 “(C) The center will provide education,
19 training, and clinical skills improvement for
20 health professionals aimed at better under-
21 standing and treatment of autism and related
22 developmental disorders; and

23 “(D) The center will identify eligible cases
24 and controls through its surveillance systems
25 and conduct research into factors which may

1 cause autism and related developmental dis-
2 orders; each program will develop or extend an
3 area of special research expertise (including,
4 but not limited to, genetics, environmental ex-
5 posure to contaminants, immunology, and other
6 relevant research specialty areas).

7 “(c) CLEARINGHOUSE.—The Secretary, acting
8 through the Director of the Centers for Disease Control
9 and Prevention, shall carry out the following:

10 “(1) The Centers for Disease Control and Pre-
11 vention shall serve as the coordinating agency for
12 autism and pervasive developmental disorders sur-
13 veillance activities through the establishment of a
14 clearinghouse for the collection and storage of data
15 generated from the monitoring programs created by
16 this section. The functions of such a clearinghouse
17 shall include facilitating the coordination of research
18 and policy development relating to the epidemiology
19 of autism and other pervasive developmental dis-
20 orders.

21 “(2) The Secretary shall coordinate the Federal
22 response to requests for assistance from State health
23 department officials regarding potential or alleged
24 autism or developmental disorder clusters.

25 “(d) ADVISORY COMMITTEE.—

1 “(1) IN GENERAL.—The Secretary shall estab-
2 lish an Advisory Committee for Autism and Perva-
3 sive developmental disorders Epidemiology Research
4 (in this section referred to as the ‘Committee’). The
5 Committee shall provide advice and recommenda-
6 tions to the Director of the Centers for Disease Con-
7 trol and Prevention on—

8 “(A) the establishment of a national au-
9 tism and pervasive developmental disorders sur-
10 veillance program;

11 “(B) the establishment of centers of excel-
12 lence in autism and pervasive developmental
13 disorders epidemiology;

14 “(C) methods and procedures to more ef-
15 fectively coordinate government and non-gov-
16 ernment programs and research on autism and
17 pervasive developmental disorders epidemiology;
18 and

19 “(D) the effective operation of autism and
20 pervasive developmental disorders epidemiology
21 research activities.

22 “(2) COMPOSITION.—

23 “(A) IN GENERAL.—The Committee shall
24 be composed of ex officio members in accord-

1 ance with subparagraph (B) and 11 appointed
2 members in accordance with subparagraph (C).

3 “(B) EX OFFICIO MEMBERS.—The fol-
4 lowing officials shall serve as ex officio members
5 of the Committee:

6 “(i) The Director of the National
7 Center for Environmental Health.

8 “(ii) The Assistant Administrator of
9 the Agency for Toxic Substances and Dis-
10 ease Registry.

11 “(iii) The Director of the National In-
12 stitute of Child Health and Human Devel-
13 opment.

14 “(iv) The Director of the National In-
15 stitute of Neurological Disorders and
16 Stroke.

17 “(C) APPOINTED MEMBERS.—Appoint-
18 ments to the Committee shall be made in ac-
19 cordance with the following:

20 “(i) Two members shall be research
21 scientists with demonstrated achievements
22 in research related to autism and related
23 developmental disorders. The scientists
24 shall be appointed by the Secretary in con-

1 sultation with the National Academy of
2 Sciences.

3 “(ii) Five members shall be represent-
4 atives of the five national organizations
5 whose primary emphasis is on research
6 into autism and other pervasive develop-
7 mental disorders. One representative from
8 each of such organizations shall be ap-
9 pointed by the Secretary in consultation
10 with the National Academy of Sciences.

11 “(iii) Two members shall be clinicians
12 whose practice is primarily devoted to the
13 treatment of individuals with autism and
14 other pervasive developmental disorders.
15 The clinicians shall be appointed by the
16 Secretary in consultation with the Institute
17 of Medicine and the National Academy of
18 Sciences.

19 “(iv) Two members shall be individ-
20 uals who are the parents or legal guardians
21 of a person or persons with autism or
22 other pervasive developmental disorders.
23 The individuals shall be appointed by the
24 Secretary in consultation with the ex offi-
25 cio members under subparagraph (B) and

1 the five national organizations referred to
2 in clause (ii).

3 “(3) ADMINISTRATIVE SUPPORT; TERMS OF
4 SERVICE; OTHER PROVISIONS.—The following apply
5 with respect to the Committee:

6 “(A) The Committee shall receive nec-
7 essary and appropriate administrative support
8 from the Department of Health and Human
9 Services.

10 “(B) Members of the Committee shall be
11 appointed for a term of three years, and may
12 serve for an unlimited number of terms if re-
13 appointed.

14 “(C) The Committee shall meet no less
15 than two times per year.

16 “(D) Members of the Committee shall not
17 receive additional compensation for their serv-
18 ice. Such members may receive reimbursement
19 for appropriate and additional expenses that are
20 incurred through service on the Committee
21 which would not have incurred had they not
22 been a member of the Committee.

23 “(e) REPORT TO CONGRESS.—The Secretary shall
24 prepare and submit to the Congress, after consultation
25 with and comment by the advisory committee under sub-

1 section (d), an annual report regarding the prevalence and
2 incidence of autism and other pervasive developmental dis-
3 orders, the results of research into the etiology of autism
4 and other pervasive developmental disorders, public health
5 responses to known or preventable causes of autism and
6 other pervasive developmental disorders, and the need for
7 additional research into promising lines of scientific in-
8 quiry.

9 “(f) AUTHORIZATION OF APPROPRIATIONS.—For the
10 purpose of carrying out this section, there are authorized
11 to be appropriated such sums as may be necessary for
12 each of the fiscal years 2001 through 2005.”.

13 **Subtitle B—Expansion, Intensifica-**
14 **tion, and Coordination of Au-**
15 **tism Activities of National Insti-**
16 **tutes of Health With Respect to**
17 **Autism**

18 **SEC. 111. SHORT TITLE.**

19 This subtitle may be cited as the “Advancement in
20 Pediatric Autism Research Act of 2000”.

1 **SEC. 112. EXPANSION, INTENSIFICATION, AND COORDINA-**
2 **TION; INFORMATION AND EDUCATION;**
3 **INTERAGENCY COORDINATING COMMITTEE.**

4 Part B of title IV of the Public Health Service Act
5 (42 U.S.C. 284 et seq.) is amended by adding at the end
6 the following section:

7 “AUTISM

8 “SEC. 409C. (a) IN GENERAL.—

9 “(1) EXPANSION OF ACTIVITIES.—The Director
10 of NIH (in this section referred to as the ‘Director’)
11 shall expand, intensify, and coordinate the activities
12 of the National Institutes of Health with respect to
13 research on autism.

14 “(2) ADMINISTRATION OF PROGRAM; COLLABO-
15 RATION AMONG AGENCIES.—The Director shall carry
16 out this section (other than subsection (b)) acting
17 through the Director of the National Institute of
18 Mental Health and in collaboration with any other
19 agencies that the Director determines appropriate.

20 “(b) INTERAGENCY COORDINATING COMMITTEE.—

21 “(1) IN GENERAL.—The Secretary shall ensure
22 that there is in operation an interagency committee
23 to be known as the ‘Autism Coordinating Com-
24 mittee’ (referred to in this subsection as the ‘Com-
25 mittee’) to coordinate all efforts within the Depart-
26 ment of Health and Human Services concerning au-

1 tism, including activities carried out through the Na-
2 tional Institutes of Health under this section and ac-
3 tivities carried out through the Centers for Disease
4 Control and Prevention under section 317H.

5 “(2) MEMBERSHIP.—The Committee shall be
6 composed of such directors of the national research
7 institutes, such directors of centers within the Cen-
8 ters for Disease Control and Prevention, and such
9 other officials within the Department of Health and
10 Human Services as the Secretary determines to be
11 appropriate. The Committee may include representa-
12 tives of other Federal agencies that serve children
13 with autism, such as the Department of Education.

14 “(3) MEETINGS.—The Committee shall meet
15 not less than twice per year.

16 “(c) CENTERS OF EXCELLENCE.—

17 “(1) IN GENERAL.—The Director shall under
18 subsection (a)(1) make awards of grants and con-
19 tracts to public or nonprofit private entities to pay
20 all or part of the cost of planning, establishing, im-
21 proving, and providing basic operating support for
22 centers of excellence regarding research on autism.

23 “(2) RESEARCH.—Each center under para-
24 graph (1) shall conduct basic and clinical research
25 into autism. Such research should include investiga-

1 tions into the cause, diagnosis, early detection, pre-
2 vention, control, and treatment of autism. These
3 centers, as a group, shall conduct research including
4 but not limited to the fields of developmental
5 neurobiology, genetics, and psychopharmacology.

6 “(3) SERVICES FOR PATIENTS.—A center under
7 paragraph (1) may expend amounts provided under
8 such paragraph to carry out a program to make in-
9 dividuals aware of opportunities to participate as
10 subjects in research conducted by the centers. The
11 program may, in accordance with such criteria as
12 the Director may establish, provide to such subjects
13 referrals for health and other services, and such pa-
14 tient care costs as are required for research. The ex-
15 tent to which the center can demonstrate availability
16 and access to clinical services shall be considered by
17 the Director in decisions about awarding the grants
18 to applicants which meet the scientific criteria for
19 funding.

20 “(4) COORDINATION OF CENTERS; REPORTS.—
21 The Director shall, as appropriate, provide for the
22 coordination of information among centers under
23 paragraph (1) and ensure regular communication
24 between such centers, and may require the periodic

1 preparation of reports on the activities of the centers
2 and the submission of the reports to the Director.

3 “(5) ORGANIZATION OF CENTERS.—Each cen-
4 ter under paragraph (1) shall use the facilities of a
5 single institution, or be formed from a consortium of
6 cooperating institutions, meeting such requirements
7 as may be prescribed by the Director.

8 “(6) NUMBER OF CENTERS; DURATION OF SUP-
9 PORT.—The Director shall provide for the establish-
10 ment of not less than five centers under paragraph
11 (1), subject to the extent of amounts made available
12 in appropriations Acts. Support of such a center
13 may be for a period not exceeding 5 years. Such pe-
14 riod may be extended for one or more additional pe-
15 riods not exceeding 5 years if the operations of such
16 center have been reviewed by an appropriate tech-
17 nical and scientific peer review group established by
18 the Director and if such group has recommended to
19 the Director that such period should be extended.

20 “(d) FACILITATION OF RESEARCH.—The Director
21 shall under subsection (a)(1) provide for a program under
22 which samples of tissues and genetic materials that are
23 of use in research on autism are donated, collected, pre-
24 served, and made available for such research. The pro-
25 gram shall be carried out in accordance with accepted sci-

1 entific and medical standards for the donation, collection,
2 and preservation of such samples.

3 “(e) INFORMATION AND EDUCATION.—

4 “(1) IN GENERAL.—The Director shall establish
5 and implement a program to provide information
6 and education on autism to health professionals and
7 the general public, including information and edu-
8 cation on advances in the diagnosis and treatment of
9 autism and training and continuing education
10 through programs for scientists, physicians, and
11 other health professionals who provide care for pa-
12 tients with autism.

13 “(2) STIPENDS.—The Director may use
14 amounts made available under this section to pro-
15 vide stipends for health professionals who are en-
16 rolled in training programs under this section.

17 “(f) PUBLIC INPUT.—The Director shall under sub-
18 section (a)(1) provide for means through which the public
19 can obtain information on the existing and planned pro-
20 grams and activities of the National Institutes of Health
21 with respect to autism and through which the Director can
22 receive comments from the public regarding such pro-
23 grams and activities.

24 “(g) ANNUAL REPORT TO CONGRESS.—The Director
25 shall prepare and submit to the appropriate committees

1 of the Congress reports regarding the activities carried out
 2 under this section. The first report shall be submitted not
 3 later than January 10, 2002, and subsequent reports shall
 4 be submitted annually thereafter.

5 “(h) FUNDING.—For the purpose of carrying out this
 6 section, there are authorized to be appropriated such sums
 7 as may be necessary for each of the fiscal years 2001
 8 through 2005. Such authorizations of appropriations are
 9 in addition to any other authorizations of appropriations
 10 that are available for such purpose.”.

11 **TITLE II—RESEARCH AND DE-**
 12 **VELOPMENT REGARDING**
 13 **FRAGILE X**

14 **SEC. 201. SHORT TITLE.**

15 This title may be cited as the “Fragile X Research
 16 Breakthrough Act of 2000”.

17 **SEC. 202. NATIONAL INSTITUTE OF CHILD HEALTH AND**
 18 **HUMAN DEVELOPMENT; RESEARCH ON FRAG-**
 19 **ILE X.**

20 Subpart 7 of part C of title IV of the Public Health
 21 Service Act is amended by adding at the end the following
 22 section:

23 “FRAGILE X

24 “SEC. 452E. (a) EXPANSION AND COORDINATION OF
 25 RESEARCH ACTIVITIES.—The Director of the Institute,
 26 after consultation with the advisory council for the Insti-

1 tute, shall expand, intensify, and coordinate the activities
2 of the Institute with respect to research on the disease
3 known as fragile X.

4 “(b) RESEARCH CENTERS.—

5 “(1) IN GENERAL.—The Director of the Insti-
6 tute, after consultation with the advisory council for
7 the Institute, shall make grants to, or enter into
8 contracts with, public or nonprofit private entities
9 for the development and operation of centers to con-
10 duct research for the purposes of improving the di-
11 agnosis and treatment of, and finding the cure for,
12 fragile X.

13 “(2) NUMBER OF CENTERS.—In carrying out
14 paragraph (1), the Director of the Institute shall, to
15 the extent that amounts are appropriated, provide
16 for the establishment of at least three fragile X re-
17 search centers.

18 “(3) ACTIVITIES.—

19 “(A) IN GENERAL.—Each center assisted
20 under paragraph (1) shall, with respect to frag-
21 ile X—

22 “(i) conduct basic and clinical re-
23 search, which may include clinical trials
24 of—

1 “(I) new or improved diagnostic
2 methods; and

3 “(II) drugs or other treatment
4 approaches; and

5 “(ii) conduct research to find a cure.

6 “(B) FEES.—A center may use funds pro-
7 vided under paragraph (1) to provide fees to in-
8 dividuals serving as subjects in clinical trials
9 conducted under subparagraph (A).

10 “(4) COORDINATION AMONG CENTERS.—The
11 Director of the Institute shall, as appropriate, pro-
12 vide for the coordination of the activities of the cen-
13 ters assisted under this section, including providing
14 for the exchange of information among the centers.

15 “(5) CERTAIN ADMINISTRATIVE REQUIRE-
16 MENTS.—Each center assisted under paragraph (1)
17 shall use the facilities of a single institution, or be
18 formed from a consortium of cooperating institu-
19 tions, meeting such requirements as may be pre-
20 scribed by the Director of the Institute.

21 “(6) DURATION OF SUPPORT.—Support may be
22 provided to a center under paragraph (1) for a pe-
23 riod not exceeding 5 years. Such period may be ex-
24 tended for one or more additional periods, each of
25 which may not exceed 5 years, if the operations of

1 such center have been reviewed by an appropriate
2 technical and scientific peer review group established
3 by the Director and if such group has recommended
4 to the Director that such period be extended.

5 “(7) AUTHORIZATION OF APPROPRIATIONS.—
6 For the purpose of carrying out this subsection,
7 there are authorized to be appropriated such sums
8 as may be necessary for each of the fiscal years
9 2001 through 2005.”.

10 **SEC. 203. NATIONAL INSTITUTE OF CHILD HEALTH AND**
11 **HUMAN DEVELOPMENT; LOAN REPAYMENT**
12 **PROGRAM REGARDING RESEARCH ON FRAG-**
13 **ILE X.**

14 Part G of title IV of the Public Health Service Act
15 (42 U.S.C. 288 et seq.) is amended by inserting after sec-
16 tion 487E the following section:

17 “LOAN REPAYMENT PROGRAM REGARDING RESEARCH ON
18 FRAGILE X

19 “SEC. 487F. (a) IN GENERAL.—The Secretary, in
20 consultation with the Director of the National Institute
21 of Child Health and Human Development, shall establish
22 a program under which the Federal Government enters
23 into contracts with qualified health professionals (includ-
24 ing graduate students) who agree to conduct research re-
25 garding fragile X in consideration of the Federal Govern-
26 ment’s agreement to repay, for each year of such service,

1 not more than \$35,000 of the principal and interest of
 2 the educational loans owed by such health professionals.

3 “(b) APPLICABILITY OF CERTAIN PROVISIONS.—

4 With respect to the National Health Service Corps Loan
 5 Repayment Program established in subpart III of part D
 6 of title III, the provisions of such subpart (including sec-
 7 tion 338B(g)(3)) shall, except as inconsistent with sub-
 8 section (a) of this section, apply to the program estab-
 9 lished in such subsection in the same manner and to the
 10 same extent as such provisions apply to the National
 11 Health Service Corps Loan Repayment Program estab-
 12 lished in such subpart.

13 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the
 14 purpose of carrying out this section, there are authorized
 15 to be appropriated such sums as may be necessary for
 16 each of the fiscal years 2001 through 2005.”.

17 **TITLE III—JUVENILE ARTHRITIS** 18 **AND RELATED CONDITIONS**

19 **SEC. 301. NATIONAL INSTITUTE OF ARTHRITIS AND MUS-**
 20 **CULOSKELETAL AND SKIN DISEASES; RE-**
 21 **SEARCH ON JUVENILE ARTHRITIS AND RE-**
 22 **LATED CONDITIONS.**

23 Subpart 4 of part C of title IV of the Public Health
 24 Service Act (42 U.S.C. 285d et seq.) is amended by insert-
 25 ing after section 442 the following section:

1 “JUVENILE ARTHRITIS AND RELATED CONDITIONS

2 “SEC. 442A. (a) EXPANSION AND COORDINATION OF
3 ACTIVITIES.—The Director of the Institute, in coordina-
4 tion with the Director of the National Institute of Allergy
5 and Infectious Diseases, shall expand and intensify the
6 programs of such Institutes with respect to research and
7 related activities concerning juvenile arthritis and related
8 conditions.

9 “(b) COORDINATION.—The Directors referred to in
10 subsection (a) shall jointly coordinate the programs re-
11 ferred to in such subsection and consult with the Arthritis
12 and Musculoskeletal Diseases Interagency Coordinating
13 Committee.

14 “(c) PEDIATRIC RHEUMATOLOGY.—The Secretary,
15 acting through the appropriate agencies of the Public
16 Health Service, shall develop a coordinated effort to help
17 ensure that a national infrastructure is in place to train
18 and develop pediatric rheumatologists to address the
19 health care services requirements of children with arthritis
20 and related conditions.

21 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
22 purpose of carrying out this section, there are authorized
23 to be appropriated such sums as may be necessary for
24 each of the fiscal years 2001 through 2005.”.

1 **SEC. 302. INFORMATION CLEARINGHOUSE.**

2 Section 438(b) of the Public Health Service Act (42
3 U.S.C. 285d–3(b)) is amended by inserting “, including
4 juvenile arthritis and related conditions,” after “diseases”.

5 **TITLE IV—REDUCING BURDEN**
6 **OF DIABETES AMONG CHIL-**
7 **DREN AND YOUTH**

8 **SEC. 401. PROGRAMS OF CENTERS FOR DISEASE CONTROL**
9 **AND PREVENTION.**

10 Part B of title III of the Public Health Service Act,
11 as amended by section 102 of this Act, is amended by in-
12 serting after section 317H the following section:

13 “DIABETES IN CHILDREN AND YOUTH

14 “SEC. 317I. (a) NATIONAL REGISTRY ON JUVENILE
15 DIABETES.—The Secretary , acting through the Director
16 of the Centers for Disease Control and Prevention, shall
17 develop a system to collect data on juvenile diabetes, in-
18 cluding with respect to incidence and prevalence, and shall
19 establish a national database for such data.

20 “(b) TYPE 2 DIABETES IN YOUTH.—The Secretary,
21 acting through the Director of the Centers for Disease
22 Control and Prevention and in consultation with the Ad-
23 ministrator of the Health Resources and Services Admin-
24 istration, shall implement a national public health effort
25 to address type 2 diabetes in youth, including—

1 “(1) enhancing surveillance systems and ex-
2 panding research to better assess the prevalence of
3 type 2 diabetes in youth and determine the extent to
4 which type 2 diabetes is incorrectly diagnosed as
5 type 1 diabetes among children;

6 “(2) assisting States in establishing coordinated
7 school health programs and physical activity and nu-
8 trition demonstration programs to control weight
9 and increase physical activity among youth; and

10 “(3) developing and improving laboratory meth-
11 ods to assist in diagnosis, treatment, and prevention
12 of diabetes including, but not limited to, developing
13 noninvasive ways to monitor blood glucose to prevent
14 hypoglycemia and improving existing glucometers
15 that measure blood glucose.

16 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the
17 purpose of carrying out this section, there are authorized
18 to be appropriated such sums as may be necessary for
19 each of the fiscal years 2001 through 2005.”.

20 **SEC. 402. PROGRAMS OF NATIONAL INSTITUTES OF**
21 **HEALTH.**

22 Subpart 3 of part C of title IV of the Public Health
23 Service Act (42 U.S.C. 285c et seq.) is amended by insert-
24 ing after section 434 the following section:

1 “JUVENILE DIABETES

2 “SEC. 434A. (a) LONG-TERM EPIDEMIOLOGY STUD-
3 IES.—

4 “(1) IN GENERAL.—The Director of the Insti-
5 tute shall conduct or support long-term epidemiology
6 studies in which individuals with type 1, or juvenile,
7 diabetes are followed for 10 years or more. Such
8 studies shall, in order to provide a valuable resource
9 for the purposes specified in paragraph (2), provide
10 for complete characterization of disease manifesta-
11 tions, appropriate medical history, elucidation of en-
12 vironmental factors, delineation of complications, re-
13 sults of usual medical treatment and a variety of
14 other potential valuable (such as samples of blood).

15 “(2) PURPOSES.—The purposes referred to in
16 paragraph (1) with respect to type 1 diabetes are
17 the following:

18 “(A) Delineation of potential environ-
19 mental triggers thought precipitating or causing
20 type 1 diabetes.

21 “(B) Delineation of those clinical charac-
22 teristics or lab measures associated with com-
23 plications of the disease.

1 “(C) Potential study population to enter
2 into clinical trials for prevention and treatment,
3 as well as genetic studies.

4 “(b) CLINICAL TRIAL INFRASTRUCTURE/INNOVATIVE
5 TREATMENTS FOR JUVENILE DIABETES.—The Secretary,
6 acting through the Director of the National Institutes of
7 Health, shall support regional clinical centers for the cure
8 of juvenile diabetes and shall through such centers provide
9 for—

10 “(1) well-characterized population of children
11 appropriate for study;

12 “(2) well-trained clinical scientists able to con-
13 duct such trials;

14 “(3) appropriate clinical settings able to house
15 such studies; and

16 “(4) appropriate statistical capability, data,
17 safety and other monitoring capacity.

18 “(c) DEVELOPMENT OF VACCINE.—The Secretary,
19 acting through the appropriate agencies of the Public
20 Health Service, shall provide for a national effort to de-
21 velop a vaccine for type 1 diabetes. Such effort shall pro-
22 vide for a combination of increased efforts in research and
23 development of candidate vaccines, coupled with appro-
24 priate ability to conduct large clinical trials in children.

1 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
 2 purpose of carrying out this section, there are authorized
 3 to be appropriated such sums as may be necessary for
 4 each of the fiscal years 2001 through 2005.”.

5 **TITLE V—ASTHMA TREATMENT** 6 **SERVICES FOR CHILDREN**

7 **SEC. 501. SHORT TITLE.**

8 This title may be cited as the “Children’s Asthma Re-
 9 lief Act of 2000”.

10 **Subtitle A—Treatment**

11 **SEC. 511. GRANTS FOR CHILDREN’S ASTHMA RELIEF.**

12 Title III of the Public Health Service Act (42 U.S.C.
 13 241 et seq.) is amended by adding at the end the following
 14 part:

15 **“PART P—ADDITIONAL PROGRAMS**

16 **“SEC. 399L. CHILDREN’S ASTHMA TREATMENT GRANTS** 17 **PROGRAM.**

18 “(a) AUTHORITY TO MAKE GRANTS.—

19 “(1) IN GENERAL.—In addition to any other
 20 payments made under this Act or title V of the So-
 21 cial Security Act, the Secretary shall award grants
 22 to eligible entities to carry out the following pur-
 23 poses:

24 “(A) To provide access to quality medical
 25 care for children who live in areas that have a

1 high prevalence of asthma and who lack access
2 to medical care.

3 “(B) To provide on-site education to par-
4 ents, children, health care providers, and med-
5 ical teams to recognize the signs and symptoms
6 of asthma, and to train them in the use of
7 medications to treat asthma and prevent its ex-
8 acerbations.

9 “(C) To decrease preventable trips to the
10 emergency room by making medication available
11 to individuals who have not previously had ac-
12 cess to treatment or education in the manage-
13 ment of asthma.

14 “(D) To provide other services, such as
15 smoking cessation programs, home modifica-
16 tion, and other direct and support services that
17 ameliorate conditions that exacerbate or induce
18 asthma.

19 “(2) CERTAIN PROJECTS.—In making grants
20 under paragraph (1), the Secretary may make
21 grants designed to develop and expand the following
22 projects:

23 “(A) Projects to provide comprehensive
24 asthma services to children in accordance with
25 the guidelines of the National Asthma Edu-

1 cation and Prevention Program (through the
2 National Heart, Lung and Blood Institute), in-
3 cluding access to care and treatment for asth-
4 ma in a community-based setting;

5 “(B) Projects to demonstrate mobile health
6 care clinics that in accordance with such guide-
7 lines provide preventive asthma care. Such
8 projects shall be evaluated and reports describ-
9 ing the findings of the evaluations shall be sub-
10 mitted to the Congress.

11 “(C) Projects to conduct validated asthma
12 management education programs for patients
13 with asthma and their families, including pa-
14 tient education regarding asthma management,
15 family education on asthma management, and
16 the distribution of materials, including displays
17 and videos, to reinforce concepts presented by
18 medical teams.

19 “(2) AWARD OF GRANTS.—

20 “(A) APPLICATION.—

21 “(i) IN GENERAL.—An eligible entity
22 shall submit an application to the Sec-
23 retary for a grant under this section in
24 such form and manner as the Secretary
25 may require.

1 “(ii) REQUIRED INFORMATION.—An
2 application submitted under this subpara-
3 graph shall include a plan for the use of
4 funds awarded under the grant and such
5 other information as the Secretary may re-
6 quire.

7 “(B) REQUIREMENT.—In awarding grants
8 under this section, the Secretary shall give pref-
9 erence to eligible entities that demonstrate that
10 the activities to be carried out under this sec-
11 tion shall be in localities within areas of known
12 or suspected high prevalence of childhood asth-
13 ma or high asthma-related mortality (relative to
14 the average asthma prevalence rates and associ-
15 ated mortality rates in the United States). Ac-
16 ceptable data sets to demonstrate a high preva-
17 lence of childhood asthma or high asthma-re-
18 lated mortality may include data from Federal,
19 State, or local vital statistics, claims data under
20 title XIX or XXI of the Social Security Act,
21 other public health statistics or surveys, or
22 other data that the Secretary, in consultation
23 with the Director of the Centers for Disease
24 Control and Prevention, deems appropriate.

1 “(3) DEFINITION OF ELIGIBLE ENTITY.—For
 2 purposes of this section, the term ‘eligible entity’
 3 means a State agency or other entity receiving funds
 4 under title V of the Social Security Act, a local com-
 5 munity, a nonprofit children’s hospital or founda-
 6 tion, or a nonprofit community-based organization.

7 “(b) COORDINATION WITH OTHER CHILDREN’S PRO-
 8 GRAMS.—An eligible entity shall identify in the plan sub-
 9 mitted as part of an application for a grant under this
 10 section how the entity will coordinate operations and ac-
 11 tivities under the grant with—

12 “(1) other programs operated in the State that
 13 serve children with asthma, including any such pro-
 14 grams operated under titles V, XIX, or XXI of the
 15 Social Security Act; and

16 “(2) one or more of the following—

17 “(A) the child welfare and foster care and
 18 adoption assistance programs under parts B
 19 and E of title IV of such Act;

20 “(B) the head start program established
 21 under the Head Start Act (42 U.S.C. 9831 et
 22 seq.);

23 “(C) the program of assistance under the
 24 special supplemental nutrition program for
 25 women, infants and children (WIC) under sec-

1 tion 17 of the Child Nutrition Act of 1966 (42
2 U.S.C. 1786);

3 “(D) local public and private elementary or
4 secondary schools; or

5 “(E) public housing agencies, as defined in
6 section 3 of the United States Housing Act of
7 1937 (42 U.S.C. 1437a).

8 “(c) EVALUATION.—An eligible entity that receives a
9 grant under this section shall submit to the Secretary an
10 evaluation of the operations and activities carried out
11 under the grant that includes—

12 “(1) a description of the health status outcomes
13 of children assisted under the grant;

14 “(2) an assessment of the utilization of asthma-
15 related health care services as a result of activities
16 carried out under the grant;

17 “(3) the collection, analysis, and reporting of
18 asthma data according to guidelines prescribed by
19 the Director of the Centers for Disease Control and
20 Prevention; and

21 “(4) such other information as the Secretary
22 may require.

23 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
24 purpose of carrying out this section, there are authorized

1 to be appropriated such sums as may be necessary for
 2 each of the fiscal years 2001 through 2005.”.

3 **SEC. 512. TECHNICAL AND CONFORMING AMENDMENTS.**

4 Title III of the Public Health Service Act (42 U.S.C.
 5 241 et seq.) is amended—

6 (1) in part L, by redesignating section 399D as
 7 section 399A;

8 (2) in part M—

9 (A) by redesignating sections 399H
 10 through 399L as sections 399B through 399F,
 11 respectively;

12 (B) in section 399B (as so redesignated),
 13 in subsection (e)—

14 (i) by striking “section 399K(b)” and
 15 inserting “subsection (b) of section 399E”;
 16 and

17 (ii) by striking “section 399C” and in-
 18 serting “such section”;

19 (C) in section 399E (as so redesignated),
 20 in subsection (c), by striking “section 399H(a)”
 21 and inserting “section 399B(a)”; and

22 (D) in section 399F (as so redesignated)—

23 (i) in subsection (a), by striking “sec-
 24 tion 399I” and inserting “section 399C”;

1 (ii) in subsection (a), by striking
2 “subsection 399J” and inserting “section
3 399D”; and

4 (iii) in subsection (b), by striking
5 “subsection 399K” and inserting “section
6 399E”;

7 (3) in part N, by redesignating section 399F as
8 section 399G; and

9 (4) in part O—

10 (A) by redesignating sections 399G
11 through 399J as sections 399H through 399K,
12 respectively;

13 (B) in section 399H (as so redesignated),
14 in subsection (b), by striking “section 399H”
15 and inserting “section 399I”;

16 (C) in section 399J (as so redesignated),
17 in subsection (b), by striking “section 399G(d)”
18 and inserting “section 399H(d)”; and

19 (D) in section 399K (as so redesignated),
20 by striking “section 399G(d)(1)” and inserting
21 “section 399H(d)(1)”.

1 **Subtitle B—Prevention Activities**

2 **SEC. 521. PREVENTIVE HEALTH AND HEALTH SERVICES**

3 **BLOCK GRANT; SYSTEMS FOR REDUCING**

4 **ASTHMA-RELATED ILLNESSES THROUGH**

5 **URBAN COCKROACH MANAGEMENT.**

6 Section 1904(a)(1) of the Public Health Service Act
7 (42 U.S.C. 300w-3(a)(1)) is amended—

8 (1) by redesignating subparagraphs (E) and
9 (F) as subparagraphs (F) and (G), respectively;

10 (2) by adding a period at the end of subpara-
11 graph (G) (as so redesignated);

12 (3) by inserting after subparagraph (D), the
13 following:

14 “(E) The establishment, operation, and coordi-
15 nation of effective and cost-efficient systems to re-
16 duce the prevalence of asthma and asthma-related
17 illnesses among urban populations, especially chil-
18 dren, by reducing the level of exposure to cockroach
19 allergen through the use of integrated pest manage-
20 ment, as applied to cockroaches. Amounts expended
21 for such systems may include the costs of building
22 maintenance and the costs of programs to promote
23 community participation in the carrying out at such
24 sites of integrated pest management, as applied to
25 cockroaches. For purposes of this subparagraph, the

term ‘integrated pest management’ means an approach to the management of pests in public facilities that combines biological, cultural, physical, and chemical tools in a way that minimizes economic, health, and environmental risks.”;

(4) in subparagraph (F) (as so redesignated), by striking “subparagraphs (A) through (D)” and inserting “subparagraphs (A) through (E)”; and

(5) in subparagraph (G) (as so redesignated), by striking “subparagraphs (A) through (E)” and inserting “subparagraphs (A) through (F)”.

Subtitle C—Coordination of Federal Activities

SEC. 531. COORDINATION THROUGH NATIONAL INSTITUTES OF HEALTH.

Subpart 2 of part C of title IV of the Public Health Service Act (42 U.S.C. 285b et seq.) is amended by inserting after section 424A the following section:

“COORDINATION OF FEDERAL ASTHMA ACTIVITIES

“SEC. 424B (a) IN GENERAL.—The Director of Institute shall, through the National Asthma Education Prevention Program Coordinating Committee—

“(1) identify all Federal programs that carry out asthma-related activities;

“(2) develop, in consultation with appropriate Federal agencies and professional and voluntary

1 health organizations, a Federal plan for responding
 2 to asthma; and

3 “(3) not later than 12 months after the date of
 4 the enactment of the Children’s Health Act of 2000,
 5 submit recommendations to the appropriate commit-
 6 tees of the Congress on ways to strengthen and im-
 7 prove the coordination of asthma-related activities of
 8 the Federal Government.

9 “(b) REPRESENTATION OF THE DEPARTMENT OF
 10 HOUSING AND URBAN DEVELOPMENT.—A representative
 11 of the Department of Housing and Urban Development
 12 shall be included on the National Asthma Education Pre-
 13 vention Program Coordinating Committee for the purpose
 14 of performing the tasks described in subsection (a).

15 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the
 16 purpose of carrying out this section, there are authorized
 17 to be appropriated such sums as may be necessary for
 18 each of the fiscal years 2001 through 2005.”.

19 **Subtitle D—Compilation of Data**

20 **SEC. 541. COMPILATION OF DATA BY CENTERS FOR DIS-** 21 **EASE CONTROL AND PREVENTION.**

22 Part B of title III of the Public Health Service Act,
 23 as amended by section 401 of this Act, is amended by in-
 24 serting after section 317I the following section:

1 “COMPILATION OF DATA ON ASTHMA

2 “SEC. 317J. (a) IN GENERAL.—The Secretary, act-
3 ing through the Director of the Centers for Disease Con-
4 trol and Prevention and in consultation with the Director
5 of the National Heart, Lung, and Blood Institute, shall—

6 “(1) conduct local asthma surveillance activities
7 to collect data on the prevalence and severity of
8 asthma and the quality of asthma management;

9 “(2) compile and annually publish data on the
10 prevalence of children suffering from asthma in each
11 State; and

12 “(3) to the extent practicable, compile and pub-
13 lish data on the childhood mortality rate associated
14 with asthma nationally.

15 “(b) NATIONAL COORDINATING COMMITTEE.—The
16 Director of the National Heart, Lung, and Blood Institute
17 shall in carrying out subsection (a) consult with the Na-
18 tional Asthma Education Prevention Program Coordi-
19 nating Committee.

20 “(c) COLLABORATIVE EFFORTS.—The activities de-
21 scribed in subsection (a)(1) may be conducted in collabo-
22 ration with eligible entities awarded a grant under section
23 399L.”.

TITLE VI—BIRTH DEFECTS
PREVENTION ACTIVITIES
Subtitle A—Folic Acid

SEC. 601. SHORT TITLE.

This subtitle may be cited as the “Folic Acid Prevention and Birth Defects Prevention Act of 2000”.

SEC. 602. PROGRAM REGARDING EFFECTS OF FOLIC ACID
IN PREVENTION OF BIRTH DEFECTS.

Part B of title III of the Public Health Service Act, as amended by section 541 of this Act, is amended by inserting after section 317J the following section:

“EFFECTS OF FOLIC ACID IN PREVENTION OF BIRTH
DEFECTS

“SEC. 317K. (a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall carry out a program (directly or through grants or contracts) for the following purposes:

“(1) To provide education and training for health professionals and the general public for purposes of explaining the effects of folic acid in preventing birth defects and for purposes of encouraging each woman of reproductive capacity (whether or not planning a pregnancy) to consume on a daily basis a dietary supplement that provides an appropriate level of folic acid.

1 “(2) To conduct research with respect to such
2 education and training, including identifying effective
3 strategies for increasing the rate of consumption
4 of folic acid by women of reproductive capacity.

5 “(3) To conduct research to increase the understanding
6 of the effects of folic acid in preventing
7 birth defects, including understanding with respect
8 to cleft lip, cleft palate, and heart defects.

9 “(4) To provide for appropriate epidemiological
10 activities regarding folic acid and birth defects, including
11 epidemiological activities regarding neural
12 tube defects.

13 “(b) CONSULTATIONS WITH STATES AND PRIVATE
14 ENTITIES.—In carrying out subsection (a), the Secretary
15 shall consult with the States and with other appropriate
16 public or private entities, including national nonprofit private
17 organizations, health professionals, and providers of
18 health insurance and health plans.

19 “(c) TECHNICAL ASSISTANCE.—The Secretary may
20 (directly or through grants or contracts) provide technical
21 assistance to public and nonprofit private entities in carrying
22 out the activities described in subsection (a).

23 “(d) EVALUATIONS.—The Secretary shall (directly or
24 through grants or contracts) provide for the evaluation of
25 activities under subsection (a) in order to determine the

1 extent to which such activities have been effective in car-
 2 rying out the purposes of the program under such sub-
 3 section, including the effects on various demographic pop-
 4 ulations. Methods of evaluation under the preceding sen-
 5 tence may include surveys of knowledge and attitudes on
 6 the consumption of folic acid and on blood folate levels.
 7 Such methods may include complete and timely moni-
 8 toring of infants who are born with neural tube defects.

9 “(e) AUTHORIZATION OF APPROPRIATIONS.—For the
 10 purpose of carrying out this section, there are authorized
 11 to be appropriated such sums as may be necessary for
 12 each of the fiscal years 2001 through 2005.”.

13 **Subtitle B—National Center on**
 14 **Birth Defects and Develop-**
 15 **mental Disabilities**

16 **SEC. 611. NATIONAL CENTER ON BIRTH DEFECTS AND**
 17 **DEVELOPMENTAL DISABILITIES.**

18 Section 317C of the Public Health Service Act (42
 19 U.S.C. 247b–4) is amended—

20 (1) by striking the heading for the section and
 21 inserting the following:

22 “NATIONAL CENTER ON BIRTH DEFECTS AND
 23 DEVELOPMENTAL DISABILITIES”;

24 (2) by striking “SEC. 317C. (a)” and all that
 25 follows through the end of subsection (a) and insert-
 26 ing the following:

1 “SEC. 317C. (a) IN GENERAL.—

2 “(1) NATIONAL CENTER.—There is established
3 within the Centers for Disease Control and Preven-
4 tion a center to be known as the National Center on
5 Birth Defects and Developmental Disabilities (re-
6 ferred to in this section as the ‘Center’), which shall
7 be headed by a director appointed by the Director of
8 the Centers for Disease Control and Prevention.

9 “(2) GENERAL DUTIES.—The Secretary shall
10 carry out programs—

11 (A) to collect, analyze, and make available
12 data on birth defects (in a manner that facili-
13 tates compliance with subsection (d)(2)), includ-
14 ing data on the causes of such defects and on
15 the incidence and prevalence of such defects;

16 (B) to operate regional centers for the con-
17 duct of applied epidemiological research on the
18 prevention of such defects; and

19 (C) to provide information and education
20 to the public on the prevention of such defects.

21 “(3) FOLIC ACID.—The Secretary shall carry
22 out section 317K through the Center.

23 “(4) CERTAIN PROGRAMS.—

24 “(A) TRANSFERS.—All programs and
25 functions described in subparagraph (B) are

1 transferred to the Center, effective on the date
2 of the enactment of the Children’s Health Act
3 of 2000.

4 “(B) RELEVANT PROGRAMS.—The pro-
5 grams and functions described in this subpara-
6 graph are all programs and functions that—

7 “(i) relate to birth defects, folic acid,
8 cerebral palsy, mental retardation, child
9 development, newborn screening, autism,
10 fragile X syndrome, fetal alcohol syndrome,
11 pediatric genetics, or disability prevention;
12 and

13 “(ii) were carried out through the Na-
14 tional Center for Environmental Health as
15 of the day before the date of the enactment
16 of the Act referred to in subparagraph (A).

17 “(C) RELATED TRANSFERS.—Personnel
18 employed in connection with the programs and
19 functions specified in subparagraph (B), and
20 amounts available for carrying out the pro-
21 grams and functions, are transferred to the Cen-
22 ter, effective on the date of the enactment of
23 the Act referred to in subparagraph (A). Such
24 transfer of amounts does not affect the period
25 of availability of the amounts, or the availability

1 of the amounts with respect to the purposes for
 2 which the amounts may be expended.”; and

3 (3) in subsection (b)(1), in the matter pre-
 4 ceding subparagraph (A), by striking “(a)(1)” and
 5 inserting “(a)(2)(A)”.

6 **TITLE VII—EARLY DETECTION,**
 7 **DIAGNOSIS, AND TREATMENT**
 8 **REGARDING HEARING LOSS**
 9 **IN INFANTS**

10 **SEC. 701. SHORT TITLE.**

11 This title may be cited as the “Newborn and Infant
 12 Hearing Screening and Intervention Act of 2000”.

13 **SEC. 702. PURPOSES.**

14 The purposes of this subtitle are to clarify the author-
 15 ity within the Public Health Service Act to authorize state-
 16 wide newborn and infant hearing screening, evaluation
 17 and intervention programs and systems, technical assist-
 18 ance, a national applied research program, and inter-
 19 agency and private sector collaboration for policy develop-
 20 ment, in order to assist the States in making progress to-
 21 ward the following goals:

22 (1) All babies born in hospitals in the United
 23 States and its territories should have a hearing
 24 screening before leaving the birthing facility. Babies
 25 born in other countries and residing in the United

1 States via immigration or adoption should have a
2 hearing screening as early as possible.

3 (2) All babies who are not born in hospitals in
4 the United States and its territories should have a
5 hearing screening within the first 3 months of life.

6 (3) Appropriate audiologic and medical evalua-
7 tions should be conducted by 3 months for all
8 newborns and infants suspected of having hearing
9 loss to allow appropriate referral and provisions for
10 audiologic rehabilitation, medical and early interven-
11 tion before the age of 6 months.

12 (4) All newborn and infant hearing screening
13 programs and systems should include a component
14 for audiologic rehabilitation, medical and early inter-
15 vention options that ensures linkage to any new and
16 existing state-wide systems of intervention and reha-
17 bilitative services for newborns and infants with
18 hearing loss.

19 (5) Public policy in regard to newborn and in-
20 fant hearing screening and intervention should be
21 based on applied research and the recognition that
22 newborns, infants, toddlers, and children who are
23 deaf or hard-of-hearing have unique language, learn-
24 ing, and communication needs, and should be the re-

1 sult of consultation with pertinent public and private
2 sectors.

3 **SEC. 703. PROGRAMS OF HEALTH RESOURCES AND SERV-**
4 **ICES ADMINISTRATION, CENTERS FOR DIS-**
5 **EASE CONTROL AND PREVENTION, AND NA-**
6 **TIONAL INSTITUTES OF HEALTH.**

7 Part P of title III of the Public Health Service Act,
8 as added by section 511 of this Act, is amended by adding
9 at the end the following section:

10 **“SEC. 399M. EARLY DETECTION, DIAGNOSIS, AND TREAT-**
11 **MENT REGARDING HEARING LOSS IN IN-**
12 **FANTS.**

13 “(a) STATEWIDE NEWBORN AND INFANT HEARING
14 SCREENING, EVALUATION AND INTERVENTION PRO-
15 GRAMS AND SYSTEMS.—The Secretary, acting through the
16 Administrator of the Health Resources and Services Ad-
17 ministration, shall make awards of grants or cooperative
18 agreements to develop statewide newborn and infant hear-
19 ing screening, evaluation and intervention programs and
20 systems for the following purposes:

21 “(1) To develop and monitor the efficacy of
22 state-wide newborn and infant hearing screening,
23 evaluation and intervention programs and systems.
24 Early intervention includes referral to schools and
25 agencies, including community, consumer, and par-

1 ent-based agencies and organizations and other pro-
2 grams mandated by part C of the Individuals with
3 Disabilities Education Act, which offer programs
4 specifically designed to meet the unique language
5 and communication needs of deaf and hard of hear-
6 ing newborns, infants, toddlers, and children.

7 “(2) To collect data on statewide newborn and
8 infant hearing screening, evaluation and intervention
9 programs and systems that can be used for applied
10 research, program evaluation and policy develop-
11 ment.

12 “(b) TECHNICAL ASSISTANCE, DATA MANAGEMENT,
13 AND APPLIED RESEARCH.—

14 “(1) CENTERS FOR DISEASE CONTROL AND
15 PREVENTION.—The Secretary, acting through the
16 Director of the Centers for Disease Control and Pre-
17 vention, shall make awards of grants or cooperative
18 agreements to provide technical assistance to State
19 agencies to complement an intramural program and
20 to conduct applied research related to newborn and
21 infant hearing screening, evaluation and intervention
22 programs and systems. The program shall develop
23 standardized procedures for data management and
24 program effectiveness and costs, such as—

1 “(A) to ensure quality monitoring of new-
2 born and infant hearing loss screening, evalua-
3 tion, and intervention programs and systems;

4 “(B) to provide technical assistance on
5 data collection and management;

6 “(C) to study the costs and effectiveness of
7 newborn and infant hearing screening, evalua-
8 tion and intervention programs and systems
9 conducted by State-based programs in order to
10 answer issues of importance to state and na-
11 tional policymakers;

12 “(D) to identify the causes and risk factors
13 for congenital hearing loss;

14 “(E) to study the effectiveness of newborn
15 and infant hearing screening, audiologic and
16 medical evaluations and intervention programs
17 and systems by assessing the health, intellectual
18 and social developmental, cognitive, and lan-
19 guage status of these children at school age;
20 and

21 “(F) to promote the sharing of data re-
22 garding early hearing loss with State-based
23 birth defects and developmental disabilities
24 monitoring programs for the purpose of identi-

1 fying previously unknown causes of hearing
2 loss.

3 “(2) NATIONAL INSTITUTES OF HEALTH.—The
4 Director of the National Institutes of Health, acting
5 through the Director of the National Institute on
6 Deafness and Other Communication Disorders, shall
7 for purposes of this section, continue a program of
8 research and development on the efficacy of new
9 screening techniques and technology, including clin-
10 ical studies of screening methods, studies on efficacy
11 of intervention, and related research.

12 “(c) COORDINATION AND COLLABORATION.—

13 “(1) IN GENERAL.—In carrying out programs
14 under this section, the Administrator of the Health
15 Resources and Services Administration, the Director
16 of the Centers for Disease Control and Prevention,
17 and the Director of the National Institutes of Health
18 shall collaborate and consult with other Federal
19 agencies; State and local agencies, including those
20 responsible for early intervention services pursuant
21 to title XIX of the Social Security Act (Medicaid
22 Early and Periodic Screening, Diagnosis and Treat-
23 ment Program); title XXI of the Social Security Act
24 (State Children’s Health Insurance Program); title
25 V of the Social Security Act (Maternal and Child

1 Health Block Grant Program); and part C of the
2 Individuals with Disabilities Education Act; con-
3 sumer groups of and that serve individuals who are
4 deaf and hard-of-hearing and their families; appro-
5 priate national medical and other health and edu-
6 cation specialty organizations; persons who are deaf
7 and hard-of-hearing and their families; other quali-
8 fied professional personnel who are proficient in deaf
9 or hard-of-hearing children's language and who pos-
10 sess the specialized knowledge, skills, and attributes
11 needed to serve deaf and hard-of-hearing newborns,
12 infants, toddlers, children, and their families; third-
13 party payers and managed care organizations; and
14 related commercial industries.

15 “(2) POLICY DEVELOPMENT.—The Adminis-
16 trator of the Health Resources and Services Admin-
17 istration, the Director of the Centers for Disease
18 Control and Prevention, and the Director of the Na-
19 tional Institutes of Health shall coordinate and col-
20 laborate on recommendations for policy development
21 at the Federal and State levels and with the private
22 sector, including consumer, medical and other health
23 and education professional-based organizations, with
24 respect to newborn and infant hearing screening,
25 evaluation and intervention programs and systems.

1 “(3) STATE EARLY DETECTION, DIAGNOSIS,
2 AND INTERVENTION PROGRAMS AND SYSTEMS; DATA
3 COLLECTION.—The Administrator of the Health Re-
4 sources and Services Administration and the Direc-
5 tor of the Centers for Disease Control and Preven-
6 tion shall coordinate and collaborate in assisting
7 States to establish newborn and infant hearing
8 screening, evaluation and intervention programs and
9 systems under subsection (a) and to develop a data
10 collection system under subsection (b).

11 “(d) RULE OF CONSTRUCTION.—Nothing in this sec-
12 tion shall be construed to preempt any State law.

13 “(e) DEFINITIONS.—For purposes of this section:

14 “(1) The term ‘audiologic evaluation’ refers to
15 procedures to assess the status of the auditory sys-
16 tem; to establish the site of the auditory disorder;
17 the type and degree of hearing loss, and the poten-
18 tial effects of hearing loss on communication; and to
19 identify appropriate treatment and referral options.
20 Referral options should include linkage to State co-
21 ordinating agencies under part C of the Individuals
22 with Disabilities Education Act or other appropriate
23 agencies, medical evaluation, hearing aid/sensory aid
24 assessment, audiologic rehabilitation treatment, na-
25 tional and local consumer, self-help, parent, and

1 education organizations, and other family-centered
2 services.

3 “(2) The terms ‘audiologic rehabilitation’ and
4 ‘audiologic intervention’ refer to procedures, tech-
5 niques, and technologies to facilitate the receptive
6 and expressive communication abilities of a child
7 with hearing loss.

8 “(3) The term ‘early intervention’ refer to pro-
9 viding appropriate services for the child with hearing
10 loss, including nonmedical services, and ensuring
11 that families of the child are provided comprehen-
12 sive, consumer-oriented information about the full
13 range of family support, training, information serv-
14 ices, communication options and are given the op-
15 portunity to consider the full range of educational
16 and program placements and options for their child.

17 “(4) The term ‘medical evaluation by a physi-
18 cian’ refers to key components including history, ex-
19 amination, and medical decision making focused on
20 symptomatic and related body systems for the pur-
21 pose of diagnosing the etiology of hearing loss and
22 related physical conditions, and for identifying ap-
23 propriate treatment and referral options.

24 “(5) The term ‘medical intervention’ refers to
25 the process by which a physician provides medical

1 diagnosis and direction for medical and/or surgical
2 treatment options of hearing loss and/or related
3 medical disorder associated with hearing loss.

4 “(6) The term ‘newborn and infant hearing
5 screening’ refers to objective physiologic procedures
6 to detect possible hearing loss and to identify
7 newborns and infants who, after rescreening, require
8 further audiologic and medical evaluations.

9 “(f) AUTHORIZATION OF APPROPRIATIONS.—

10 “(1) STATEWIDE NEWBORN AND INFANT HEAR-
11 ING SCREENING, EVALUATION AND INTERVENTION
12 PROGRAMS AND SYSTEMS.—For the purpose of car-
13 rying out subsection (a), there are authorized to be
14 appropriated to the Health Resources and Services
15 Administration such sums as may be necessary for
16 each of the fiscal years 2001 through 2005.

17 “(2) TECHNICAL ASSISTANCE, DATA MANAGE-
18 MENT, AND APPLIED RESEARCH; CENTERS FOR DIS-
19 EASE CONTROL AND PREVENTION.—For the purpose
20 of carrying out subsection (b)(1), there are author-
21 ized to be appropriated to the Centers for Disease
22 Control and Prevention such sums as may be nec-
23 essary for each of the fiscal years 2001 through
24 2005.

1 “(3) TECHNICAL ASSISTANCE, DATA MANAGE-
 2 MENT, AND APPLIED RESEARCH; NATIONAL INSTI-
 3 TUTE ON DEAFNESS AND OTHER COMMUNICATION
 4 DISORDERS.—For the purpose of carrying out sub-
 5 section (b)(2), there are authorized to be appro-
 6 priated to the National Institute on Deafness and
 7 Other Communication Disorders such sums as may
 8 be necessary for each of the fiscal years 2001
 9 through 2005.”.

10 **TITLE VIII—CHILDREN AND** 11 **EPILEPSY**

12 **SEC. 801. NATIONAL PUBLIC HEALTH CAMPAIGN ON EPI-** 13 **LEPSY; SEIZURE DISORDER DEMONSTRATION** 14 **PROJECTS IN MEDICALLY UNDERSERVED** 15 **AREAS.**

16 Subpart I of part D of title III of the Public Health
 17 Service Act (42 U.S.C. 254b) is amended by adding at
 18 the end the following section:

19 **“SEC. 330E. EPILEPSY; SEIZURE DISORDER.**

20 “(a) NATIONAL PUBLIC HEALTH CAMPAIGN.—

21 “(1) IN GENERAL.—The Secretary shall develop
 22 and implement public health surveillance, education,
 23 research, and intervention strategies to improve the
 24 lives of persons with epilepsy, with a particular em-
 25 phasis on children. Such projects may be carried out

1 by the Secretary directly and through awards of
2 grants or contracts to public or nonprofit private en-
3 tities. The Secretary may directly or through such
4 awards provide technical assistance with respect to
5 the planning, development, and operation of such
6 projects.

7 “(2) CERTAIN ACTIVITIES.—Activities under
8 paragraph (1) shall include—

9 “(A) expanding current surveillance activi-
10 ties through existing monitoring systems and
11 improving registries that maintain data on indi-
12 viduals with epilepsy, including children;

13 “(B) enhancing research activities on pa-
14 tient management and control of epilepsy;

15 “(C) implementing public and professional
16 information and education programs regarding
17 epilepsy, including initiatives which promote ef-
18 fective management and control of the disease
19 through children’s programs which are targeted
20 to parents, schools, daycare providers, patients;

21 “(D) undertaking educational efforts with
22 the media, providers of health care, schools and
23 others regarding stigmas and secondary disabil-
24 ities related to epilepsy and seizures, and also
25 its affects on youth;

1 “(E) utilizing and expanding partnerships
2 with organizations with experience addressing
3 the health and related needs of people with dis-
4 abilities; and

5 “(F) other activities the Secretary deems
6 appropriate.

7 “(3) COORDINATION OF ACTIVITIES.—The Sec-
8 retary shall ensure that activities under this sub-
9 section are coordinated as appropriate with other
10 agencies of the Public Health Service that carry out
11 activities regarding epilepsy and seizure.

12 “(b) SEIZURE DISORDER; DEMONSTRATION
13 PROJECTS IN MEDICALLY UNDERSERVED AREAS.—

14 “(1) IN GENERAL.—The Secretary, acting
15 through the Administrator of the Health Resources
16 and Services Administration, may make grants to
17 States and local governments for the purpose of car-
18 rying out demonstration projects to improve access
19 to health and other services regarding seizures to en-
20 courage early detection and treatment in children
21 and others residing in medically underserved areas.

22 “(2) APPLICATION FOR GRANT.—The Secretary
23 may make a grant under paragraph (1) only if the
24 application for the grant is submitted to the Sec-
25 retary and the application is in such form, is made

1 in such matter, and contains such agreements, as-
 2 surances, and information as the Secretary deter-
 3 mines to be necessary to carry out this subsection.

4 “(c) DEFINITIONS.—For purposes of this section:

5 “(1) The term “epilepsy” refers to a chronic
 6 and serious neurological condition which produces
 7 excessive electrical discharges in the brain causing
 8 recurring seizures affecting all life activities. The
 9 Secretary may revise the definition of such term as
 10 the Secretary.

11 “(2) The term “medically underserved” has the
 12 meaning applicable under section 799B(6).

13 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
 14 purpose of carrying out this section, there are authorized
 15 to be appropriated such sums as may be necessary for
 16 each of the fiscal years 2001 through 2005.”.

17 **TITLE IX—SAFE MOTHERHOOD;**
 18 **INFANT HEALTH PROMOTION**
 19 **Subtitle A—Safe Motherhood Moni-**
 20 **toring and Prevention Research**

21 **SEC. 901. SHORT TITLE.**

22 This title may be cited as the “Safe Motherhood Mon-
 23 itoring and Prevention Research Act”.

1 **SEC. 902. MONITORING; PREVENTION RESEARCH AND**
2 **OTHER ACTIVITIES.**

3 Part B of title III of the Public Health Service Act,
4 as amended by section 602 of this Act, is amended by in-
5 serting after section 317K the following section:

6 “SAFE MOTHERHOOD

7 “SEC. 317L. (a) MONITORING.—

8 “(1) PURPOSE.—The purpose of this subsection
9 is to develop monitoring systems at the local, State,
10 and national level to better understand the burden
11 of maternal complications and mortality and to de-
12 crease the disparities among population at risk of
13 death and complications from pregnancy.

14 “(2) ACTIVITIES.—For the purpose described in
15 paragraph (1), the Secretary, acting through the Di-
16 rector of the Centers for Disease Control and Pre-
17 vention, may carry out the following activities:

18 “(A) the Secretary may establish and im-
19 plement a national monitoring and surveillance
20 program to identify and promote the investiga-
21 tion of deaths and severe complications that
22 occur during pregnancy.

23 “(B) The Secretary may expand the Preg-
24 nancy Risk Assessment Monitoring System to
25 provide surveillance and collect data in each of
26 the 50 States.

1 “(C) The Secretary may expand the Ma-
2 ternal and Child Health Epidemiology Program
3 to provide technical support, financial assist-
4 ance, or the time-limited assignment of senior
5 epidemiologists to maternal and child health
6 programs in each of the 50 States.

7 “(b) PREVENTION RESEARCH.—

8 “(1) PURPOSE.—The purpose of this subsection is to
9 provide the Secretary with the authority to further expand
10 research concerning risk factors, prevention strategies,
11 and the roles of the family, health care providers and the
12 community in safe motherhood.

13 “(2) RESEARCH.—The Secretary, acting
14 through the Director of the Centers for Disease
15 Control and Prevention, may carry out activities to
16 expand research relating to—

17 “(A) encouraging preconception coun-
18 seling, especially for at risk populations such as
19 diabetics;

20 “(B) the identification of critical compo-
21 nents of prenatal delivery and postpartum care;

22 “(C) the identification of outreach and
23 support services, such as folic acid education,
24 that are available for pregnant women;

1 “(D) the identification of women who are
2 at high risk for complications;

3 “(E) preventing preterm delivery;

4 “(F) preventing urinary tract infections;

5 “(G) preventing unnecessary caesarean
6 sections;

7 “(H) an examination of the higher rates of
8 maternal mortality among african american
9 women;

10 “(I) an examination of the relationship be-
11 tween domestic violence and maternal complica-
12 tions and mortality;

13 “(J) preventing smoking, alcohol and ille-
14 gal drug usage before, during and after preg-
15 nancy;

16 “(K) preventing infections that cause ma-
17 ternal and infant complications; and

18 “(L) other areas determined appropriate
19 by the Secretary.

20 “(c) PREVENTION PROGRAMS.—

21 “(1) IN GENERAL.—The Secretary, acting
22 through the Director of the Centers for Disease
23 Control and Prevention, may carry out activities to
24 promote safe motherhood, including—

1 “(A) public education campaigns on
 2 healthy pregnancies and the building of part-
 3 nerships with outside organizations concerned
 4 about safe motherhood;

5 “(B) education programs for physicians,
 6 nurses and other health care providers; and

7 “(C) activities to promote community sup-
 8 port services for pregnant women.

9 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
 10 purpose of carrying out this section, there are authorized
 11 to be appropriated such sums as may be necessary for
 12 each of the fiscal years 2001 through 2005.”.

13 **Subtitle B—Pregnant Mothers and** 14 **Infants Health Promotion**

15 **SEC. 911. SHORT TITLE.**

16 This subtitle may be cited as the “Pregnant Mothers
 17 and Infants Health Protection Act”.

18 **SEC. 912. PROGRAMS REGARDING PRENATAL AND POST-** 19 **NATAL HEALTH.**

20 Part B of title III of the Public Health Service Act,
 21 as amended by section 902 of this Act, is amended by in-
 22 serting after section 317L the following section:

23 “PRENATAL AND POSTNATAL HEALTH

24 “SEC. 317M. (a) IN GENERAL.—The Secretary, act-
 25 ing through the Director of the Centers for Disease Con-
 26 trol and Prevention, shall carry out programs—

1 “(1) to collect, analyze, and make available data
2 on prenatal smoking, alcohol and illegal drug usage,
3 including data on the implications of such activities
4 and on the incidence and prevalence of such activi-
5 ties and their implications;

6 “(2) to conduct applied epidemiological research
7 on the prevention of prenatal and postnatal smoking,
8 alcohol and illegal drug usage;

9 “(3) to support, conduct, and evaluate the ef-
10 fectiveness of educational and cessation programs;
11 and

12 “(4) to provide information and education to
13 the public on the prevention and implications of pre-
14 natal and postnatal smoking, alcohol and illegal drug
15 usage.

16 “(b) GRANTS.—In carrying out subsection (a), the
17 Secretary may award grants to and enter into contracts
18 with States, local governments, scientific and academic in-
19 stitutions, Federally qualified health centers, and other
20 public and nonprofit entities, and may provide technical
21 and consultative assistance to such entities.

22 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the
23 purpose of carrying out this section, there are authorized
24 to be appropriated such sums as may be necessary for
25 each of the fiscal years 2001 through 2005.”.

1 **TITLE X—REVISION AND**
2 **EXTENSION OF PROGRAMS**
3 **Subtitle A—Pediatric Research**
4 **Initiative**

5 **SEC. 1001. SHORT TITLE.**

6 This subtitle may be cited as the “Pediatric Research
7 Initiative Act of 2000”.

8 **SEC. 1002. ESTABLISHMENT OF PEDIATRIC RESEARCH**
9 **INITIATIVE.**

10 Part B of title IV of the Public Health Service Act,
11 as amended by section 112 of this Act, is amended by add-
12 ing at the end the following:

13 “PEDIATRIC RESEARCH INITIATIVE

14 “SEC. 409D. (a) ESTABLISHMENT.—The Secretary
15 shall establish within the Office of the Director of NIH
16 a Pediatric Research Initiative (referred to in this section
17 as the ‘Initiative’). The Initiative shall be headed by the
18 Director of NIH.

19 “(b) PURPOSE.—The purpose of the Initiative is to
20 provide funds to enable the Director of NIH to provide—

21 “(1) increased support for pediatric biomedical
22 research within the National Institutes of Health to
23 ensure that the expanding opportunities for advance-
24 ment in scientific investigations and care for chil-
25 dren are realized;

1 “(2) enhanced collaborative efforts among the
2 Institutes to support multidisciplinary research in
3 the areas that the Director deems most promising;
4 and

5 “(3) the development of adequate pediatric clin-
6 ical trials and pediatric use information to promote
7 the safer and more effective use of prescription
8 drugs in the pediatric population.

9 “(c) DUTIES.—In carrying out subsection (b), the Di-
10 rector of NIH shall—

11 “(1) consult with the Director of the National
12 Institute of Child Health and Human Development
13 and the Directors of the other national research in-
14 stitutes, in considering their requests for new or ex-
15 panded pediatric research efforts, and consult with
16 the Administrator of the Health Resources and Serv-
17 ices Administration and other advisors as the Direc-
18 tor determines to be appropriate;

19 “(2) have broad discretion in the allocation of
20 any Initiative assistance among the Institutes,
21 among types of grants, and between basic and clin-
22 ical research so long as the—

23 “(A) assistance is directly related to the ill-
24 nesses and conditions of children; and

1 “(B) assistance is extramural in nature;
2 and

3 “(3) be responsible for the oversight of any
4 newly appropriated Initiative funds and annually re-
5 port to Congress and the public on the extent of the
6 total extramural support for pediatric research
7 across the NIH, including the specific support and
8 research awards allocated through the Initiative.

9 “(d) AUTHORIZATION.—For the purpose of carrying
10 out this section, there are authorized to be appropriated
11 such sums as may be necessary for each of the fiscal years
12 2001 through 2005.

13 “(e) TRANSFER OF FUNDS.—The Director of NIH
14 may transfer amounts appropriated under this section to
15 any of the Institutes for a fiscal year to carry out the pur-
16 poses of the Initiative under this section.”.

17 **SEC. 1003. INVESTMENT IN TOMORROW’S PEDIATRIC**
18 **RESEARCHERS.**

19 Subpart 7 of part C of title IV of the Public Health
20 Service Act, as amended by section 921 of this Act, is
21 amended by adding at the end the following:

22 “INVESTMENT IN TOMORROW’S PEDIATRIC RESEARCHERS

23 “SEC. 452G. (a) IN GENERAL.—In order to ensure
24 the future supply of researchers dedicated to the care and
25 research needs of children, the Director of the Institute,
26 after consultation with the Administrator of the Health

1 Resources and Services Administration, shall support ac-
 2 tivities to provide for—

3 “(1) an increase in the number and size of in-
 4 stitutional training grants to pediatric departments
 5 of medical schools and to children’s hospitals; and

6 “(2) an increase in the number of career devel-
 7 opment awards for health professionals who are in
 8 pediatric specialties or subspecialties and intend to
 9 build careers in pediatric basic and clinical research.

10 “(b) AUTHORIZATION.—For the purpose of carrying
 11 out this section, there are authorized to be appropriated
 12 such sums as may be necessary for each of the fiscal years
 13 2001 through 2005.”.

14 **Subtitle B—Other Programs**

15 **SEC. 1011. CHILDHOOD IMMUNIZATIONS.**

16 Section 317(j)(1) of the Public Health Service Act
 17 (42 U.S.C. 247b(j)(1)) is amended in the first sentence
 18 by striking “1998” and all that follows and inserting
 19 “1998 through 2003.”.

20 **SEC. 1012. SCREENINGS, REFERRALS, AND EDUCATION RE-** 21 **GARDING LEAD POISONING.**

22 Section 317A(l)(1) of the Public Health Service Act
 23 (42 U.S.C. 247b–1(l)(1)) is amended by striking “1994”
 24 and all that follows and inserting “1994 through 2003.”.

**TITLE XI—CHILDHOOD
SKELETAL MALIGNANCIES**

**SEC. 1101. PROGRAMS OF CENTERS FOR DISEASE CONTROL
AND PREVENTION AND NATIONAL INSTI-
TUTES OF HEALTH.**

Part P of title III of the Public Health Service Act,
as amended by section 703 of this Act, is amended by add-
ing at the end the following section:

“SEC. 399N. CHILDHOOD SKELETAL MALIGNANCIES.

“(a) IN GENERAL.—The Secretary, acting as appro-
priate through the Director of the Centers for Disease
Control and Prevention and the Director of the National
Institutes of Health, shall study environmental and other
risk factors for childhood skeletal cancers, and carry out
projects to improve outcomes among children with child-
hood skeletal cancers and resultant secondary conditions,
including limb loss. Such projects shall be carried out by
the Secretary directly and through awards of grants or
contracts to public or nonprofit entities.

“(b) CERTAIN ACTIVITIES.—Activities under sub-
section (a) include—

“(1) the expansion of current demographic data
collection and population surveillance efforts to in-
clude childhood skeletal cancers nationally;

1 “(2) the development of a uniform reporting
2 system under which treating physicians, hospitals,
3 clinics, and states report the diagnosis of childhood
4 skeletal cancers, including relevant associated epide-
5 miological data; and

6 “(3) support for the National Limb Loss Infor-
7 mation Center to address, in part, the primary and
8 secondary needs of persons who experience childhood
9 skeletal cancers in order to prevent or minimize the
10 disabling nature of these cancers.

11 “(c) COORDINATION OF ACTIVITIES.—The Secretary
12 shall assure that activities under this section are coordi-
13 nated as appropriate with other agencies of the Public
14 Health Service that carry out activities focused on child-
15 hood cancers and limb loss.

16 “(d) DEFINITION.—For purposes of this section, the
17 term ‘childhood skeletal cancer’ refers to any malignancy
18 originating in the connective tissue of a person before skel-
19 etal maturity including the appendicular and axial skel-
20 eton. The Secretary may for purposes of this section revise
21 the definition of such term to the extent determined by
22 the Secretary to be appropriate.

23 “(e) AUTHORIZATION OF APPROPRIATIONS.—For the
24 purpose of carrying out this section, there are authorized

1 to be appropriated such sums as may be necessary for
 2 each of the fiscal years 2001 through 2005.”.

3 **TITLE XII—ADOPTION**

4 **AWARENESS**

5 **Subtitle A—Infant Adoption** 6 **Awareness**

7 **SEC. 1201. SHORT TITLE.**

8 This subtitle may be cited as the “Infant Adoption
 9 Awareness Act of 2000”.

10 **SEC. 1202. GRANTS REGARDING INFANT ADOPTION AWARE-** 11 **NESS.**

12 Subpart I of part D of title III of the Public Health
 13 Service Act, as amended by section 801 of this Act, is
 14 amended by adding at the end the following section:

15 **“SEC. 330F. CERTAIN SERVICES FOR PREGNANT WOMEN.**

16 **“(a) INFANT ADOPTION AWARENESS.—**

17 **“(1) IN GENERAL.—**The Secretary shall make
 18 grants to national, regional, or local adoption organi-
 19 zations for the purpose of developing and imple-
 20 menting programs to train the designated staff of el-
 21 igible health centers in providing adoption informa-
 22 tion and referrals to pregnant women on an equal
 23 basis with all other courses of action included in
 24 nondirective counseling.

25 **“(2) BEST-PRACTICES GUIDELINES.—**

1 “(A) IN GENERAL.—A condition for the re-
2 ceipt of a grant under paragraph (1) is that the
3 adoption organization involved agree that, in
4 providing training under such paragraph, the
5 organization will follow the guidelines developed
6 under subparagraph (B).

7 “(B) PROCESS FOR DEVELOPMENT OF
8 GUIDELINES.—

9 “(i) IN GENERAL.—The Secretary
10 shall establish and supervise a process de-
11 scribed in clause (ii) in which the partici-
12 pants are—

13 “(I) an appropriate number and
14 variety of adoption organizations that
15 have expertise in all models of adop-
16 tion practice and that represent all
17 members of the adoption triad (birth
18 mother, infant, and adoptive parent);
19 and

20 “(II) affected public health enti-
21 ties.

22 “(ii) DESCRIPTION OF PROCESS.—The
23 process referred to in clause (i) is a proc-
24 ess in which the participants described in
25 such clause collaborate to develop best-

practices guidelines on the provision of adoption information and referrals to pregnant women on an equal basis with all other courses of action included in non-directive counseling.

“(iii) DATE CERTAIN FOR DEVELOPEMENT.—The Secretary shall ensure that the guidelines described in clause (ii) are developed not later than 180 days after the date of the enactment of the Children’s Health Act of 2000.

“(C) RELATION TO AUTHORITY FOR GRANTS.—The Secretary may not make any grant under paragraph (1) before the date on which the guidelines under subparagraph (B) are developed.

“(3) USE OF GRANT.—

“(A) IN GENERAL.—With respect to a grant under paragraph (1)—

“(i) an adoption organization may expend the grant to carry out the programs directly or through grants to or contracts with other adoption organizations;

“(ii) the purposes for which the adoption organization expends the grant may

1 include the development of a training cur-
2 riculum, consistent with the guidelines de-
3 veloped under paragraph (2)(B); and

4 “(iii) a condition for the receipt of the
5 grant is that the adoption organization
6 agree that, in providing training for the
7 designated staff of eligible health centers,
8 such organization will make reasonable ef-
9 forts to ensure that the individuals who
10 provide the training are individuals who
11 are experienced in providing adoption in-
12 formation and referrals in the geographic
13 areas in which the eligible health centers
14 are located, and that the designated staff
15 receive the training in such areas.

16 “(B) RULE OF CONSTRUCTION REGARDING
17 TRAINING OF TRAINERS.—With respect to indi-
18 viduals who under a grant under paragraph (1)
19 provide training for the designated staff of eli-
20 gible health centers (referred to in this subpara-
21 graph as ‘trainers’), subparagraph (A)(iii) may
22 not be construed as establishing any limitation
23 regarding the geographic area in which the
24 trainers receive instruction in being such train-
25 ers. A trainer may receive such instruction in a

1 different geographic area than the area in
2 which the trainer trains (or will train) the des-
3 ignated staff of eligible health centers.

4 “(4) ADOPTION ORGANIZATIONS; ELIGIBLE
5 HEALTH CENTERS; OTHER DEFINITIONS.—For pur-
6 poses of this section:

7 “(A) The term ‘adoption organization’
8 means a national, regional, or local
9 organization—

10 “(i) among whose foci are adoption;

11 “(ii) that is knowledgeable on the
12 process for adopting a child and on pro-
13 viding adoption information and referrals
14 to pregnant women; and

15 “(iii) that is a nonprofit private enti-
16 ty.

17 “(B) The term ‘designated staff’, with re-
18 spect to an eligible health center, means staff of
19 the center who provide pregnancy or adoption
20 information and referrals (or will provide such
21 information and referrals after receiving train-
22 ing under a grant under paragraph (1)).

23 “(C) The term ‘eligible health centers’
24 means public and nonprofit private entities that

1 provide health-related services to pregnant
2 women.

3 “(5) TRAINING FOR CERTAIN ELIGIBLE
4 HEALTH CENTERS.—A condition for the receipt of a
5 grant under paragraph (1) is that the adoption orga-
6 nization involved agree to make reasonable efforts to
7 ensure that the eligible health centers with respect
8 to which training under the grant is provided
9 include—

10 “(A) eligible health centers that receive
11 grants under section 1001 (relating to vol-
12 untary family planning projects);

13 “(B) eligible health centers that receive
14 grants under section 330 (relating to commu-
15 nity health centers, migrant health centers, and
16 centers regarding homeless individuals and resi-
17 dents of public housing); and

18 “(C) eligible health centers that receive
19 grants under this Act for the provision of serv-
20 ices in schools.

21 “(6) PARTICIPATION OF CERTAIN ELIGIBLE
22 HEALTH CLINICS.—In the case of eligible health cen-
23 ters that receive grants under section 330 or 1001:

24 “(A) The Secretary shall require that,
25 within a reasonable period after the Secretary

1 begins making grants under paragraph (1),
2 such centers make reasonable efforts to encour-
3 age the designated staff of the centers to under-
4 go training through the program under such
5 paragraph.

6 “(B) All costs of such centers in obtaining
7 the training shall be reimbursed by the organi-
8 zation that provides the training, using grants
9 under paragraph (1).

10 “(C) Beginning one year after the date on
11 which the Secretary first makes grants under
12 paragraph (1), the Secretary shall commence a
13 study to evaluate the extent of compliance of
14 health centers with subparagraph (A) and the
15 extent to which nondirective counseling and re-
16 ferrals includes adoption information and refer-
17 rals. After conducting the study for a reason-
18 able period of time, the Secretary shall submit
19 to the appropriate committees of the Congress
20 a reporting describing the findings of the study.

21 “(b) REQUIREMENTS REGARDING FEDERALLY-
22 FUNDED FAMILY PLANNING SERVICES.—The Secretary
23 shall require that each program providing voluntary family
24 planning services with a grant from the Secretary provide

1 nondirective counseling and referrals on all the options,
 2 including but not limited to adoption.

3 “(c) APPLICATION FOR GRANT.—The Secretary may
 4 make a grant under subsection (a) only if an application
 5 for the grant is submitted to the Secretary and the appli-
 6 cation is in such form, is made in such manner, and con-
 7 tains such agreements, assurances, and information as the
 8 Secretary determines to be necessary to carry out this sec-
 9 tion.

10 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
 11 purpose of carrying out this section, there are authorized
 12 to be appropriated such sums as may be necessary for
 13 each of the fiscal years 2001 through 2005.”.

14 **Subtitle B—Special Needs Adoption** 15 **Awareness**

16 **SEC. 1211. SPECIAL NEEDS ADOPTION PROGRAMS; PUBLIC** 17 **AWARENESS CAMPAIGN AND OTHER ACTIVI-** 18 **TIES.**

19 Subpart I of part D of title III of the Public Health
 20 Service Act, as amended by section 1202 of this Act, is
 21 amended by adding at the end the following section:

1 **“SEC. 330G. SPECIAL NEEDS ADOPTION PROGRAMS; PUBLIC**
2 **AWARENESS CAMPAIGN AND OTHER ACTIVI-**
3 **TIES.**

4 “(a) SPECIAL NEEDS ADOPTION AWARENESS CAM-
5 PAIGN.—

6 “(1) IN GENERAL.—The Secretary shall,
7 through making grants to nonprofit private entities,
8 provide for the planning, development, and carrying
9 out of a national campaign to provide information to
10 the public regarding the adoption of children with
11 special needs.

12 “(2) INPUT ON PLANNING AND DEVELOP-
13 MENT.—In providing for the planning and develop-
14 ment of the national campaign under paragraph (1),
15 the Secretary shall provide for input from a number
16 and variety of adoption organizations throughout the
17 States in order that the full national diversity of in-
18 terests among adoption organizations is represented
19 in the planning and development of the campaign.

20 “(3) CERTAIN FEATURES.—With respect to the
21 national campaign under paragraph (1):

22 “(A) The campaign shall be directed at
23 various populations, taking into account as ap-
24 propriate differences among geographic regions,
25 and shall be carried out in the language and

1 cultural context that is most appropriate to the
2 population involved.

3 “(B) The means through which the cam-
4 paign may be carried out include—

5 “(i) placing public service announce-
6 ments on television, radio, and billboards;
7 and

8 “(ii) providing information through
9 means that the Secretary determines will
10 reach individuals who are most likely to
11 adopt children with special needs.

12 “(C) The campaign shall provide informa-
13 tion on the subsidies and supports that are
14 available to individuals regarding the adoption
15 of children with special needs.

16 “(D) The Secretary may provide that the
17 placement of public service announcements, and
18 the dissemination of brochures and other mate-
19 rials, is subject to review by the Secretary.

20 “(4) MATCHING REQUIREMENT.—

21 “(A) IN GENERAL.—With respect to the
22 costs of the activities to be carried out by an
23 entity pursuant to paragraph (1), a condition
24 for the receipt of a grant under such paragraph
25 is that the entity agree to make available (di-

1 rectly or through donations from public or pri-
2 vate entities) non-Federal contributions toward
3 such costs in an amount that is not less than
4 50 percent of such costs (\$1 for each \$1 pro-
5 vided in the grant).

6 “(B) DETERMINATION OF AMOUNT CON-
7 TRIBUTED.—Non-Federal contributions under
8 subparagraph (A) may be in cash or in kind,
9 fairly evaluated, including plant, equipment, or
10 services. Amounts provided by the Federal Gov-
11 ernment, or services assisted or subsidized to
12 any significant extent by the Federal Govern-
13 ment, may not be included in determining the
14 amount of such contributions.

15 “(b) NATIONAL RESOURCES PROGRAM.—The Sec-
16 retary shall (directly or through grant or contract) carry
17 out a program that, through toll-free telecommunications,
18 makes available to the public information regarding the
19 adoption of children with special needs. Such information
20 shall include the following:

21 “(1) A list of national, State, and regional or-
22 ganizations that provide services regarding such
23 adoptions, including exchanges and other informa-
24 tion on communicating with the organizations. The

1 list shall represent the full national diversity of
2 adoption organizations.

3 “(2) Information beneficial to individuals who
4 adopt such children, including lists of support
5 groups for adoptive parents and other postadoptive
6 services.

7 “(c) OTHER PROGRAMS.—With respect to the adop-
8 tion of children with special needs, the Secretary shall
9 make grants—

10 “(1) to provide assistance to support groups for
11 adoptive parents, adopted children, and siblings of
12 adopted children; and

13 “(2) to carry out studies to identify the reasons
14 for adoption disruptions.

15 “(d) APPLICATION FOR GRANT.—The Secretary may
16 make an award of a grant or contract under this section
17 only if an application for the award is submitted to the
18 Secretary and the application is in such form, is made in
19 such manner, and contains such agreements, assurances,
20 and information as the Secretary determines to be nec-
21 essary to carry out this section.

22 “(e) FUNDING.—For the purpose of carrying out this
23 section, there are authorized to be appropriated such sums
24 as may be necessary for each of the fiscal years 2001
25 through 2005.”.

1 **TITLE XIII—TRAUMATIC BRAIN**
2 **INJURY**

3 **SEC. 1301. SHORT TITLE.**

4 This title may be cited as the “Traumatic Brain In-
5 jury Act Amendments of 2000”.

6 **SEC. 1302. PROGRAMS OF CENTERS FOR DISEASE CONTROL**
7 **AND PREVENTION.**

8 (a) IN GENERAL.—Section 393A of the Public
9 Health Service Act (42 U.S.C. 280b–1b) is amended—

10 (1) in subsection (b)—

11 (A) in paragraph (1), by striking “and” at
12 the end;

13 (B) in paragraph (2), by striking the pe-
14 riod and inserting “; and”; and

15 (C) by adding at the end the following:

16 “(3) the implementation of a national education
17 and awareness campaign regarding such injury (in
18 conjunction with the program of the Secretary re-
19 garding health-status goals for 2010, commonly re-
20 ferred to as Healthy People 2010), including the na-
21 tional dissemination of information on—

22 “(A) incidence and prevalence;

23 “(B) secondary conditions arising from
24 traumatic brain injury upon discharge from
25 hospitals and trauma centers.”;

1 (2) in subsection (d)—

2 (A) in the second sentence, by striking
3 “anoxia due to near drowning.” and inserting
4 “anoxia.”; and

5 (B) in the third sentence, by inserting be-
6 fore the period the following: “, after consulta-
7 tion with States and other appropriate public or
8 nonprofit private entities”.

9 (b) NATIONAL REGISTRY.—Part J of title III of the
10 Public Health Service Act (42 U.S.C. 280b et seq.) is
11 amended by inserting after section 393A the following sec-
12 tion:

13 “NATIONAL PROGRAM FOR TRAUMATIC BRAIN INJURY
14 REGISTRIES

15 “SEC. 393B. (a) IN GENERAL.—The Secretary, act-
16 ing through the Director of the Centers for Disease Con-
17 trol and Prevention, may make grants to States or their
18 designees to operate the State’s traumatic brain injury
19 registry, and to academic institutions to conduct applied
20 research that will support the development of such reg-
21 istries, to collect data concerning—

22 “(1) demographic information about each trau-
23 matic brain injury;

24 “(2) information about the circumstances sur-
25 rounding the injury event associated with each trau-
26 matic brain injury;

1 “(3) administrative information about the
2 source of the collected information, dates of hos-
3 pitalization and treatment, and the date of injury;
4 and

5 “(4) information characterizing the clinical as-
6 pects of the traumatic brain injury, including the se-
7 verity of the injury, the types of treatments received,
8 and the types of services utilized.”.

9 **SEC. 1303. PROGRAMS OF NATIONAL INSTITUTES OF**
10 **HEALTH.**

11 (a) INTERAGENCY PROGRAM.—Section 1261(d)(4) of
12 the Public Health Service Act (42 U.S.C. 300d–61(d)(4))
13 is amended—

14 (1) in subparagraph (A), by striking “degree of
15 injury” and inserting “degree of brain injury”;

16 (2) in subparagraph (B), by striking “acute in-
17 jury” and inserting “acute brain injury”; and

18 (3) in subparagraph (D), by striking “injury
19 treatment” and inserting “brain injury treatment”.

20 (b) DEFINITION.—Section 1261(h)(4) of the Public
21 Health Service Act (42 U.S.C. 300d–61(h)(4)) is
22 amended—

23 (1) in the second sentence, by striking “anoxia
24 due to near drowning.” and inserting “anoxia.”; and

1 (2) in the third sentence, by inserting before
2 the period the following: “, after consultation with
3 States and other appropriate public or nonprofit pri-
4 vate entities”.

5 (c) AUTHORIZATION OF APPROPRIATIONS.—Section
6 1261 of the Public Health Service Act (42 U.S.C. 300d–
7 61) is amended by adding at the end the following:

8 “(i) AUTHORIZATION OF APPROPRIATIONS.—For the
9 purpose of carrying out this section, there are authorized
10 to be appropriated such sums as may be necessary for
11 each of the fiscal years 2000 through 2004.”.

12 **SEC. 1304. PROGRAMS OF HEALTH RESOURCES AND SERV-**
13 **ICES ADMINISTRATION.**

14 Section 1252 of the Public Health Service Act (42
15 U.S.C. 300d–51) is amended—

16 (1) in subsection (b)(3)—

17 (A) in subparagraph (A)(iv), by striking
18 “representing traumatic brain injury survivors”
19 and inserting “representing individuals with
20 traumatic brain injury”; and

21 (B) in subparagraph (B), by striking “who
22 are survivors of” and inserting “with”;

23 (2) in subsection (c)—

24 (A) in paragraph (1), by striking “, in
25 cash,”; and

1 (B) in paragraph (2), by amending the
2 paragraph to read as follows:

3 “(2) DETERMINATION OF AMOUNT CONTRIB-
4 UTED.—Non-Federal contributions under paragraph
5 (1) may be in cash or in kind, fairly evaluated, in-
6 cluding plant, equipment, or services. Amounts pro-
7 vided by the Federal Government, or services as-
8 sisted or subsidized to any significant extent by the
9 Federal Government, may not be included in deter-
10 mining the amount of such contributions.”;

11 (3) by designating subsections (e) through (h)
12 as subsections (g) through (j), respectively; and

13 (4) by inserting after subsection (d) the fol-
14 lowing subsections:

15 “(e) CONTINUATION OF PREVIOUSLY AWARDED
16 DEMONSTRATION PROJECTS.—A State that received a
17 grant under this section prior to the date of enactment
18 of the Children’s Health Act of 2000 may compete for new
19 project grants under this section after such date of enact-
20 ment.

21 “(f) USE OF STATE GRANTS.—

22 “(1) COMMUNITY SERVICES AND SUPPORTS.—A
23 State shall (directly or through awards of contracts
24 to nonprofit private entities) use amounts received
25 under a grant under this section for the following:

1 “(A) To develop, change, or enhance com-
2 munity-based service delivery systems that in-
3 clude timely access to comprehensive appro-
4 priate services and supports. Such service and
5 supports—

6 “(i) shall promote full participation by
7 individuals with brain injury and their
8 families in decision making regarding the
9 services and supports; and

10 “(ii) shall be designed for children
11 and other individuals with traumatic brain
12 injury.

13 “(B) To focus on outreach to underserved
14 and inappropriately served individuals, such as
15 individuals in institutional settings, individuals
16 with low socioeconomic resources, individuals in
17 rural communities, and individuals in culturally
18 and linguistically diverse communities.

19 “(C) To award contracts to nonprofit enti-
20 ties for consumer or family service access train-
21 ing, consumer support, peer mentoring, and
22 parent to parent programs.

23 “(D) To provide individual and family
24 service coordination or case management sys-
25 tems.

1 “(E) To support other needs identified by
2 the advisory board under subsection (b) for the
3 State involved.

4 “(2) BEST PRACTICES.—

5 “(A) IN GENERAL.—State services and
6 supports provided under a grant under this sec-
7 tion shall reflect the best practices in the field
8 of traumatic brain injury, shall be in compli-
9 ance with title II of the Americans with Disabil-
10 ities Act of 1990, and shall be supported by
11 quality assurance measures as well as state-of-
12 the-art health care and integrated community
13 supports, regardless of the severity of injury.

14 “(B) DEMONSTRATION BY STATE AGEN-
15 CY.—The State agency responsible for admin-
16 istering amounts received under a grant under
17 this section shall demonstrate or express a will-
18 ingness to obtain expertise and knowledge of
19 traumatic brain injury and the unique needs as-
20 sociated with traumatic brain injury.

21 “(3) STATE CAPACITY BUILDING.—A State may
22 use amounts received under a grant under this sec-
23 tion to—

24 “(A) educate consumers and families;

1 “(B) train professionals in public and pri-
2 vate sector financing (such as third party pay-
3 ers, State agencies, community-based providers,
4 schools, and educators);

5 “(C) develop or improve case management
6 or service coordination systems;

7 “(D) develop best practices in areas such
8 as family or consumer support, return to work,
9 housing or supportive living personal assistance
10 services, assistive technology and devices, be-
11 havioral health services, substance abuse serv-
12 ices, and traumatic brain injury treatment and
13 rehabilitation;

14 “(E) tailor existing State systems to pro-
15 vide accommodations to the needs of individuals
16 with brain injury (including systems adminis-
17 tered by the State departments responsible for
18 health, mental health, labor, education, mental
19 retardation/developmental disorders, transpor-
20 tation, and correctional systems);

21 “(F) improve data sets coordinated across
22 systems and other needs identified by a State
23 plan supported by its advisory council; and

24 “(G) develop capacity within targeted com-
25 munities.”;

1 (5) in subsection (g) (as so redesignated), by
 2 striking “agencies of the Public Health Service” and
 3 inserting “Federal agencies”;

4 (6) in subsection (i) (as redesignated by para-
 5 graph (3))—

6 (A) in the second sentence, by striking
 7 “anoxia due to near drowning.” and inserting
 8 “anoxia.”; and

9 (B) in the third sentence, by inserting be-
 10 fore the period the following: “, after consulta-
 11 tion with States and other appropriate public or
 12 nonprofit private entities”; and

13 (7) in subsection (j) (as so redesignated), by
 14 amending the subsection to read as follows:

15 “(j) AUTHORIZATION OF APPROPRIATIONS.—For the
 16 purpose of carrying out this section, there are authorized
 17 to be appropriated such sums as may be necessary for
 18 each of the fiscal years 2001 through 2005.”.

19 **TITLE XIV—PREVENTION AND** 20 **CONTROL OF INJURIES**

21 **SEC. 1401. AUTHORIZATION OF APPROPRIATIONS FOR PRO-** 22 **GRAMS OF CENTERS FOR DISEASE CONTROL** 23 **AND PREVENTION.**

24 Section 394A of the Public Health Service Act (42
 25 U.S.C. 280b–3) is amended by striking “and” after

1 “1994” and by inserting before the period the following:
 2 “, and such sums as may be necessary for each of the
 3 fiscal years 2001 through 2005.”.

4 **TITLE XV—HEALTHY START**
 5 **INITIATIVE**

6 **SEC. 1501. SHORT TITLE.**

7 This title may be cited as the “Healthy Start Initia-
 8 tive Continuation Act”.

9 **SEC. 1502. CONTINUATION OF HEALTHY START PROGRAM.**

10 Subpart I of part D of title III of the Public Health
 11 Service Act, as amended by section 1203 of this Act, is
 12 amended by adding at the end the following section:

13 **“SEC. 330H. HEALTHY START FOR INFANTS.**

14 **“(a) IN GENERAL.—**

15 **“(1) CONTINUATION AND EXPANSION OF PRO-**
 16 **GRAM.—**The Secretary, acting through the Adminis-
 17 trator of the Health Resources and Services Admin-
 18 istration, Maternal and Child Health Bureau, shall
 19 under authority of this section continue in effect the
 20 Healthy Start Initiative and may, during fiscal year
 21 2001 and subsequent years, carry out such program
 22 on a national basis.

23 **“(2) DEFINITION.—**For purposes of paragraph
 24 (1), the term ‘Healthy Start Initiative’ is a reference
 25 to the program that, as an initiative to reduce the

1 rate of infant mortality and improve perinatal out-
2 comes, makes grants for project areas with high an-
3 nual rates of infant mortality and that, prior to the
4 effective date of this section, was a demonstration
5 program carried out under section 301.

6 “(3) ADDITIONAL GRANTS.— Effective upon in-
7 creased funding beyond fiscal year 1999 for such
8 Initiative, additional grants may be made to States
9 to assist communities with technical assistance, rep-
10 lication of successful projects, and State policy for-
11 mation to reduce infant and maternal mortality and
12 morbidity.

13 “(b) REQUIREMENTS FOR MAKING GRANTS.—In
14 making grants under subsection (a), the Secretary shall
15 require that applicants (in addition to meeting all eligi-
16 bility criteria established by the Secretary) establish, for
17 project areas under such subsection, community-based
18 consortia of individuals and organizations (including agen-
19 cies responsible for administering block grant programs
20 under title V of the Social Security Act, consumers of
21 project services, public health departments, hospitals,
22 health centers under section 330, and other significant
23 sources of health care services) that are appropriate for
24 participation in projects under subsection (a).

1 “(c) COORDINATION.—Recipients of grants under
2 subsection (a) shall coordinate their services and activities
3 with the State agency or agencies that administer block
4 grant programs under title V of the Social Security Act
5 in order to promote cooperation, integrity, and dissemina-
6 tion of information with Statewide systems and with other
7 community services funded under the Maternal and Child
8 Health Block Grant.

9 “(d) RULE OF CONSTRUCTION.—Except to the extent
10 inconsistent with this section, this section may not be con-
11 strued as affecting the authority of the Secretary to make
12 modifications in the program carried out under subsection
13 (a).

14 “(e) MEDICALLY APPROPRIATE ULTRASOUND SERV-
15 ICES; MEDICALLY APPROPRIATE SERVICES FOR AT-RISK
16 MOTHERS AND INFANTS.—

17 “(1) IN GENERAL.—The Secretary may make
18 grants to health care entities to provide—

19 “(A) for pregnant women, ultrasound serv-
20 ices provided by qualified health care profes-
21 sionals upon medical indication and referral
22 from health care professionals who provide com-
23 prehensive prenatal services; and

1 “(B) for pregnant women or infants, other
2 health services (including prenatal care, genetic
3 counseling, and fetal and other surgery) that—

4 “(i) are determined by a qualified
5 treating health care professional to be
6 medically appropriate in order to prevent
7 or mitigate congenital defects (including
8 but not limited to spina bifida and
9 hydrocephaly) or other serious obstetric
10 complications (including but not limited to
11 placenta previa, premature rupture of
12 membranes, or preeclampsia); and

13 “(ii) are provided during pregnancy or
14 during the first year after birth.

15 “(2) ELIGIBLE PROJECT AREA.—The Secretary
16 may make a grant under paragraph (1) only if the
17 geographic area in which services under the grant
18 will be provided is a geographic area in which a
19 project under subsection (a) is being carried out,
20 and if the Secretary determines that the grant will
21 add to or expand the level of health services avail-
22 able in such area to pregnant women and infants.

23 “(3) TRANSPORTATION AND SUBSISTENCE EX-
24 PENSES FOR CERTAIN PATIENTS.—The purposes for
25 which a grant under paragraph (1)(B) may be ex-

1 pended include paying, on behalf of a pregnant
2 woman who is in need of the health services de-
3 scribed in such paragraph, transportation and sub-
4 sistence expenses to assist the pregnant woman in
5 obtaining such health services from the grantee in-
6 volved. The Secretary may establish such restrictions
7 regarding payments under the preceding sentence as
8 the Secretary determines to be appropriate.

9 “(4) CERTAIN CONDITIONS.—A condition for
10 the receipt of a grant under paragraph (1) is that
11 the applicant for the grant agree as follows:

12 “(A) In the case of a grant under para-
13 graph (1)(A), if ultrasound services indicate
14 that there is a fetal anomaly or other serious
15 obstetric complication, the applicant will refer
16 the pregnant woman involved for appropriate
17 medical services, including, as appropriate, for
18 health services described in paragraph (1)(B)
19 provided by grantees under such paragraph.

20 “(B) If the applicant provides nondirective
21 pregnancy counseling to patients and is not
22 subject to the condition under section 330F(b),
23 such counseling provided by the applicant to pa-
24 tients will include (but is not limited to) the
25 provision of adoption information and referrals.

1 “(5) RELATIONSHIP TO PAYMENTS UNDER
2 OTHER PROGRAMS.—A grant may be made under
3 paragraph (1) only if the applicant involved agrees
4 that the grant will not be expended to pay the ex-
5 penses of providing any service under such para-
6 graph to a pregnant woman to the extent that pay-
7 ment has been made, or can reasonably be expected
8 to be made, with respect to such expenses—

9 “(A) under any State compensation pro-
10 gram, under an insurance policy, or under any
11 Federal or State health benefits program; or

12 “(B) by an entity that provides health
13 services on a prepaid basis.

14 “(6) EVALUATION BY GENERAL ACCOUNTING
15 OFFICE.—

16 “(A) IN GENERAL.—During fiscal year
17 2004, the Comptroller General of the United
18 States shall conduct an evaluation of activities
19 under grants under paragraph (1) in order to
20 determine whether the activities have been ef-
21 fective in serving the needs of pregnant women
22 with respect to ultrasound services and the
23 other health services described in paragraph
24 (1)(B). The evaluation shall include an analysis
25 of whether such activities have been effective in

1 reducing the disparity in health status between
2 the general population and individuals who are
3 members of racial or ethnic minority groups.
4 Not later than January 10, 2005, the Comp-
5 troller General shall submit to the Committee
6 on Commerce in the House of Representatives,
7 and to the Committee on Health, Education,
8 Labor, and Pensions in the Senate, a report de-
9 scribing the findings of the evaluation.

10 “(B) RELATION TO GRANTS REGARDING
11 MEDICALLY APPROPRIATE SERVICES FOR AT-
12 RISK MOTHERS AND INFANTS.—Before the date
13 on which the evaluation under subparagraph
14 (A) is submitted in accordance with such
15 subparagraph—

16 “(i) the Secretary shall ensure that
17 there are not more than three grantees
18 under paragraph (1)(B); and

19 “(ii) an entity is not eligible to receive
20 grants under such paragraph unless the
21 entity has substantial experience in pro-
22 viding the health services described in such
23 paragraph.

24 “(e) FUNDING.—

25 “(1) GENERAL PROGRAM.—

1 “(A) AUTHORIZATION OF APPROPRIA-
2 TIONS.—For the purpose of carrying out this
3 section (other than subsection (e)), there are
4 authorized to be appropriated such sums as
5 may be necessary for each of the fiscal years
6 2001 through 2005.

7 “(B) ALLOCATIONS.—

8 “(i) PROGRAM ADMINISTRATION.—Of
9 the amounts appropriated under subpara-
10 graph (A) for a fiscal year, the Secretary
11 may reserve up to 5 percent for coordina-
12 tion, dissemination, technical assistance,
13 and data activities that are determined by
14 the Secretary to be appropriate for car-
15 rying out the program under this section.

16 “(ii) EVALUATION.—Of the amounts
17 appropriated under subparagraph (A) for a
18 fiscal year, the Secretary may reserve up
19 to 1 percent for evaluations of projects car-
20 ried out under subsection (a). Each such
21 evaluation shall include a determination of
22 whether such projects have been effective
23 in reducing the disparity in health status
24 between the general population and indi-

1 viduals who are members of racial or eth-
2 nic minority groups.

3 “(2) MEDICALLY APPROPRIATE ULTRASOUND
4 SERVICES; MEDICALLY APPROPRIATE SERVICES FOR
5 AT-RISK MOTHERS AND INFANTS.—

6 “(A) AUTHORIZATION OF APPROPRIA-
7 TIONS.—For the purpose of carrying out sub-
8 section (e), there are authorized to be appro-
9 priated such sums as may be necessary for each
10 of the fiscal years 2001 through 2005.

11 “(B) ALLOCATION.—Of the amounts ap-
12 propriated under subparagraph (A) for a fiscal
13 year, the Secretary shall make available not less
14 than 10 percent for providing ultrasound serv-
15 ices under subsection (d)(1)(A) (provided by
16 qualified health care professionals upon medical
17 indication and referral from health care profes-
18 sionals who provide comprehensive prenatal
19 services) through visits by mobile units to com-
20 munities that are eligible for services under
21 subsection (a).”.

1 **TITLE XVI—ORAL HEALTH PRO-**
2 **MOTION AND DISEASE PRE-**
3 **VENTION**

4 **SEC. 1601. ORAL HEALTH PROMOTION AND DISEASE**
5 **PREVENTION.**

6 Part B of title III of the Public Health Service Act,
7 as amended by section 912 of this Act, is amended by in-
8 serting after section 317M the following section:

9 “ORAL HEALTH PROMOTION AND DISEASE PREVENTION
10 “SEC. 317N. (a) GRANTS TO INCREASE RESOURCES
11 FOR COMMUNITY WATER FLUORIDATION.—

12 “(1) IN GENERAL.—The Secretary, acting
13 through the Director of the Centers for Disease
14 Control and Prevention, may make grants to States
15 and Indian tribes for the purpose of increasing the
16 resources available for community water fluorida-
17 tion.

18 “(2) USE OF FUNDS.—A State shall use
19 amounts provided under a grant under paragraph
20 (1)—

21 “(A) to purchase fluoridation equipment;

22 “(B) to train fluoridation engineers;

23 “(C) to develop educational materials on
24 the benefits of fluoridation; or

1 “(D) to support the infrastructure nec-
2 essary to monitor and maintain the quality of
3 water fluoridation.

4 “(b) COMMUNITY WATER FLUORIDATION.—

5 “(1) IN GENERAL.—The Secretary, acting
6 through the Director of the Centers for Disease
7 Control and Prevention and in collaboration with the
8 Director of the Indian Health Service, shall establish
9 a demonstration project that is designed to assist
10 rural water systems in successfully implementing the
11 water fluoridation guidelines of the Centers for Dis-
12 ease Control and Prevention that are entitled “Engi-
13 neering and Administrative Recommendations for
14 Water Fluoridation, 1995” (referred to in this sub-
15 section as the ‘EARWF’).

16 “(2) REQUIREMENTS.—

17 “(A) COLLABORATION.—In collaborating
18 under paragraph (1), the Directors referred to
19 in such paragraph shall ensure that technical
20 assistance and training are provided to tribal
21 programs located in each of the 12 areas of the
22 Indian Health Service. The Director of the In-
23 dian Health Service shall provide coordination
24 and administrative support to tribes under this
25 section.

1 “(B) GENERAL USE OF FUNDS.—Amounts
2 made available under paragraph (1) shall be
3 used to assist small water systems in improving
4 the effectiveness of water fluoridation and to
5 meet the recommendations of the EARWF.

6 “(C) FLUORIDATION SPECIALISTS.—

7 “(i) IN GENERAL.—In carrying out
8 this subsection, the Secretary shall provide
9 for the establishment of fluoridation spe-
10 cialist engineering positions in each of the
11 Dental Clinical and Preventive Support
12 Centers through which technical assistance
13 and training will be provided to tribal
14 water operators, tribal utility operators
15 and other Indian Health Service personnel
16 working directly with fluoridation projects.

17 “(ii) LIAISON.—A fluoridation spe-
18 cialist shall serve as the principal technical
19 liaison between the Indian Health Service
20 and the Centers for Disease Control and
21 Prevention with respect to engineering and
22 fluoridation issues.

23 “(iii) CDC.—The Director of the Cen-
24 ters for Disease Control and Prevention

1 shall appoint individuals to serve as the
2 fluoridation specialists.

3 “(D) IMPLEMENTATION.—The project es-
4 tablished under this subsection shall be
5 planned, implemented and evaluated over the 5-
6 year period beginning on the date on which
7 funds are appropriated under this section and
8 shall be designed to serve as a model for im-
9 proving the effectiveness of water fluoridation
10 systems of small rural communities.

11 “(3) EVALUATION.—In conducting the ongoing
12 evaluation as provided for in paragraph (2)(D), the
13 Secretary shall ensure that such evaluation
14 includes—

15 “(A) the measurement of changes in water
16 fluoridation compliance levels resulting from as-
17 sistance provided under this section;

18 “(B) the identification of the administra-
19 tive, technical and operational challenges that
20 are unique to the fluoridation of small water
21 systems;

22 “(C) the development of a practical model
23 that may be easily utilized by other tribal, state,
24 county or local governments in improving the

1 quality of water fluoridation with emphasis on
2 small water systems; and

3 “(D) the measurement of any increased
4 percentage of Native Americans or Alaskan Na-
5 tives who receive the benefits of optimally fluo-
6 ridated water.

7 “(c) SCHOOL-BASED DENTAL SEALANT PROGRAM.—

8 “(1) IN GENERAL.—The Secretary, acting
9 through the Director of the Centers for Disease
10 Control and Prevention and in collaboration with the
11 Administrator of the Health Resources and Services
12 Administration, may award grants to States and In-
13 dian tribes to provide for the development of school-
14 based dental sealant programs to improve the access
15 of children to sealants.

16 “(2) USE OF FUNDS.—A State shall use
17 amounts received under a grant under paragraph (1)
18 to provide funds to eligible school-based entities or
19 to public elementary or secondary schools to enable
20 such entities or schools to provide children in second
21 and sixth grades with access to dental care and den-
22 tal sealant services. Such services shall be provided
23 by licensed dental health professionals in accordance
24 with State practice licensing laws.

1 “(3) ELIGIBILITY.—To be eligible to receive
2 funds under paragraph (1), an entity shall—

3 “(A) prepare and submit to the State an
4 application at such time, in such manner and
5 containing such information as the state may
6 require; and

7 “(B) be a public elementary or secondary
8 school—

9 “(i) that is located in an urban area
10 in which and more than 50 percent of the
11 student population is participating in fed-
12 eral or state free or reduced meal pro-
13 grams; or

14 “(ii) that is located in a rural area
15 and, with respect to the school district in
16 which the school is located, the district in-
17 volved has a median income that is at or
18 below 235 percent of the poverty line, as
19 defined in section 673(2) of the Commu-
20 nity Services Block Grant Act (42 U.S.C.
21 9902(2)).

22 “(d) DEFINITIONS.—For purposes of this section, the
23 term ‘Indian tribe’ means an Indian tribe or tribal organi-
24 zation as defined in section 4(b) and section 4(c) of the
25 Indian Self-Determination and Education Assistance Act.

1 “(e) AUTHORIZATION OF APPROPRIATIONS.—For the
2 purpose of carrying out this section, there are authorized
3 to be appropriated such sums as may be necessary for
4 each of the fiscal years 2001 through 2005.”.

5 **TITLE XVII—VACCINE**
6 **COMPENSATION PROGRAM**

7 **SEC. 1701. SHORT TITLE.**

8 This title may be cited as the “Vaccine Injury Com-
9 pensation Program Amendments of 2000.”.

10 **SEC. 1702. CONTENT OF PETITIONS.**

11 (a) IN GENERAL.—Section 2111(c)(1)(D) of the
12 Public Health Service Act (42 U.S.C. 300aa–11(c)(1)(D))
13 is amended by striking “and” at the end and inserting
14 “or (iii) suffered such illness, disability, injury, or condi-
15 tion from the vaccine which resulted in inpatient hos-
16 pitalization and surgical intervention, and”.

17 (b) EFFECTIVE DATE.—The amendment made by
18 subsection (a) takes effect upon the date of the enactment
19 of this Act, including with respect to petitions under sec-
20 tion 2111 of the Public Health Service Act that are pend-
21 ing on such date.

22 **TITLE XVIII—HEPATITIS C**

23 **SEC. 1801. SHORT TITLE.**

24 This title may be cited as the “Hepatitis C and Chil-
25 dren Act of 2000”.

1 **SEC. 1802. SURVEILLANCE AND EDUCATION REGARDING**
2 **HEPATITIS C.**

3 Part B of title III of the Public Health Service Act,
4 as amended by section 1601 of this Act, is amended by
5 inserting after section 317N the following section:

6 “SURVEILLANCE AND EDUCATION REGARDING HEPATITIS
7 C VIRUS

8 “SEC. 317O. (a) IN GENERAL.—The Secretary, act-
9 ing through the Director of the Centers for Disease Con-
10 trol and Prevention, may (directly and through grants to
11 public and nonprofit private entities) provide for programs
12 to carry out the following:

13 “(1) To cooperate with the States in imple-
14 menting a national system to determine the inci-
15 dence and prevalence of cases of infection with hepa-
16 titis C virus, including the reporting of chronic hepa-
17 titis C cases.

18 “(2) To identify and contact individuals who
19 became infected with such virus as a result of receiv-
20 ing blood transfusions prior to July 1992 when the
21 individuals were infants, small children, or adoles-
22 cents.

23 “(3) To provide appropriate referrals for coun-
24 seling, testing, and medical treatment of individuals
25 identified under paragraph (2) and to ensure, to the

1 extent practicable, the provision of appropriate fol-
2 low-up services.

3 “(4) To develop and disseminate public infor-
4 mation and education programs for the detection
5 and control of hepatitis C, with priority given to re-
6 cipients of blood transfusions; women who gave birth
7 by caesarean section; children who were high-risk
8 neonates; veterans of the Armed Forces; and health
9 professionals.

10 “(5) To improve the education, training, and
11 skills of health professionals in the detection and
12 control of cases of infection with hepatitis C, with
13 priority given to pediatricians and other primary
14 care physicians.

15 “(b) LABORATORY PROCEDURES.—The Secretary
16 may (directly and through grants to public and nonprofit
17 private entities) carry out programs to provide for im-
18 provements in the quality of clinical-laboratory procedures
19 regarding hepatitis C, including reducing variability in
20 laboratory results on hepatitis C antibody and PCR test-
21 ing.

22 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the
23 purpose of carrying out this section, there are authorized
24 to be appropriated such sums as may be necessary for
25 each of the fiscal years 2001 through 2005.”.

1 **TITLE XIX—NIH INITIATIVE ON**
 2 **AUTOIMMUNE DISEASES**

3 **SEC. 1901. SHORT TITLE.**

4 This title may be cited as the “NIH Autoimmune
 5 Diseases Initiative Act of 2000”.

6 **SEC. 1902. JUVENILE DIABETES, JUVENILE ARTHRITIS,**
 7 **LUPUS, MULTIPLE SCLEROSIS, AND OTHER**
 8 **AUTOIMMUNE-DISEASES; INITIATIVE**
 9 **THROUGH DIRECTOR OF NATIONAL INSTI-**
 10 **TUTES OF HEALTH.**

11 Part B of title IV of the Public Health Service Act,
 12 as amended by section 1002 of this Act, is amended by
 13 adding at the end the following:

14 “AUTOIMMUNE DISEASES

15 “SEC. 409E. (a) EXPANSION, INTENSIFICATION, AND
 16 COORDINATION OF ACTIVITIES.—

17 “(1) IN GENERAL.—The Director of NIH shall
 18 expand, intensify, and coordinate research and other
 19 activities of the National Institutes of Health with
 20 respect to juvenile-onset diabetes, rheumatoid arthri-
 21 tis, systemic lupus erthematosus, multiple sclerosis,
 22 Sjogren’s syndrome, scleroderma, chronic fatigue
 23 syndrome, Crohn’s disease and colitis (in this section
 24 referred to as ‘autoimmune diseases’).

1 “(2) ALLOCATIONS BY DIRECTOR OF NIH.—

2 With respect to amounts appropriated to carry out
3 this section for a fiscal year, the Director of NIH
4 shall allocate the amounts among the national re-
5 search institutes that are carrying out paragraph
6 (1).

7 “(3) ADDITIONAL DISEASES OR DISORDERS.—

8 In addition to the diseases or disorders specified in
9 paragraph (1), the term ‘autoimmune disease’ in-
10 cludes for purposes of this section such other dis-
11 eases or disorders as the Secretary determines to be
12 appropriate.

13 “(b) COORDINATING COMMITTEE.—

14 “(1) IN GENERAL.—The Secretary shall estab-
15 lish a committee to be known as Autoimmune Dis-
16 eases Coordinating Committee (referred to in this
17 subsection as the ‘Coordinating Committee’).

18 “(2) DUTIES.—The Coordinating Committee
19 shall, with respect to autoimmune diseases—

20 “(A) provide for the coordination of the ac-
21 tivities of the national research institutes; and

22 “(B) coordinate the aspects of all Federal
23 health programs and activities relating to such
24 diseases in order to assure the adequacy and
25 technical soundness of such programs and ac-

1 tivities and in order to provide for the full com-
2 munication and exchange of information nec-
3 essary to maintain adequate coordination of
4 such programs and activities.

5 “(3) COMPOSITION.—The Coordinating Com-
6 mittee shall be composed of the directors of each of
7 the national research institutes involved in research
8 with respect to autoimmune diseases and representa-
9 tives of all other Federal departments and agencies
10 whose programs involve health functions or respon-
11 sibilities relevant to such diseases, including the
12 Centers for Disease Control and Prevention and the
13 Food and Drug Administration.

14 “(4) CHAIR.—From among the members of the
15 Coordinating Committee, the Committee shall des-
16 ignate an individual to serve as the chair of the
17 Committee. With respect to autoimmune diseases,
18 the Chair shall serve as the principal advisor to the
19 Secretary, the Assistant Secretary for Health, and
20 the Director of NIH, and shall provide advice to the
21 Director of the Centers for Disease Control and Pre-
22 vention, the Commissioner of Food and Drugs, and
23 other relevant agencies.

24 “(5) FULL-TIME STAFF.—The Secretary shall
25 ensure that the Coordinating Committee is staffed

1 and supported by not fewer than three scientists or
2 health professionals for whom such service is a full-
3 time Federal position. The Secretary shall in addi-
4 tion ensure that the Committee is provided with
5 such administrative staff and support as may be
6 necessary to carry out the duties of the Committee.

7 “(c) ADVISORY COUNCIL.—

8 “(1) IN GENERAL.—The Secretary shall estab-
9 lish an advisory council to be known as the Auto-
10 immune Diseases Public Advisory Council (referred
11 to in this subsection as the ‘Advisory Council’).

12 “(2) DUTIES.—The Advisory Council shall pro-
13 vide to the Director of NIH and the Coordinating
14 Committee under subsection (b) recommendations on
15 carrying out this section, including the plan under
16 subsection (d).

17 “(3) COMPOSITION.—The Advisory Council
18 shall be composed exclusively of not more than 18
19 members appointed to the Council by the Secretary
20 from among individuals who are not officers or em-
21 ployees of the United States. The Secretary shall en-
22 sure that the membership of the Advisory Council
23 includes—

1 “(A) scientists or health professionals who
2 are knowledgeable with respect to autoimmune
3 diseases;

4 “(B) representatives of autoimmune dis-
5 ease patient advocacy organizations, including
6 organizations advocating on behalf of diseases
7 affecting small patient populations; and

8 “(C) patients and parents of children with
9 such diseases, including autoimmune diseases
10 affecting small patient populations.

11 “(d) PLAN FOR NIH ACTIVITIES.—

12 “(1) IN GENERAL.—The Coordinating Com-
13 mittee shall develop a plan for conducting and sup-
14 porting research and education on autoimmune dis-
15 eases through the national research institutes, shall
16 review the plan not less frequently than once each
17 fiscal year, and shall revise the plan as appropriate.

18 The plan shall—

19 “(A) provide for a broad range of research
20 and education activities relating to biomedical,
21 psychosocial, and rehabilitative issues, including
22 studies of the disproportionate impact of such
23 diseases on women; and

1 “(B) establish priorities among the pro-
2 grams and activities of the National Institutes
3 of Health regarding such diseases.

4 “(2) CERTAIN ELEMENTS OF PLAN.—The plan
5 under paragraph (1) shall, with respect to auto-
6 immune diseases, provide for the following:

7 “(A) Research to determine the reasons
8 underlying the incidence and prevalence of the
9 diseases.

10 “(B) Basic research concerning the eti-
11 ology and causes of the diseases.

12 “(C) Epidemiological studies to address
13 the frequency and natural history of the dis-
14 eases, including any differences among the
15 sexes and among racial and ethnic groups.

16 “(D) The development of improved screen-
17 ing techniques.

18 “(E) Clinical research for the development
19 and evaluation of new treatments, including
20 new biological agents.

21 “(F) Information and education programs
22 for health care professionals and the public.

23 “(3) RECOMMENDATIONS OF ADVISORY COUN-
24 CIL.—In developing the plan under paragraph (1),
25 and reviewing and revising the plan, the Coordi-

1 nating Committee shall consider the recommenda-
2 tions of the Advisory Council regarding the plan.

3 “(4) IMPLEMENTATION OF PLAN.—The Direc-
4 tor of NIH shall ensure that programs and activities
5 of the National Institutes of Health regarding auto-
6 immune diseases are implemented in accordance
7 with the plan under paragraph (1).

8 “(e) REPORTS TO CONGRESS.—The Coordinating
9 Committee under subsection (b)(1) shall annually submit
10 to the Committee on Commerce of the House of Rep-
11 resentatives, and the Committee on Health, Education,
12 Labor and Pensions of the Senate, a report that describes
13 the research, education, and other activities on auto-
14 immune diseases being conducted or supported through
15 the national research institutes, and that in addition in-
16 cludes the following:

17 “(1) The plan under subsection (d)(1) (or revi-
18 sions to the plan, as the case may be).

19 “(2) The recommendations of the advisory
20 council under subsection (c) regarding the plan (or
21 revisions, as the case may be).

22 “(3) Provisions specifying the amounts ex-
23 pended by the National Institutes of Health with re-
24 spect to each of the autoimmune diseases included in
25 the plan.

1 “(4) Provisions identifying particular projects
2 or types of projects that should in the future be con-
3 ducted or supported by the national research insti-
4 tutes or other entities in the field of research on
5 autoimmune diseases.

6 “(f) AUTHORIZATION OF APPROPRIATIONS.—For the
7 purpose of carrying out this section, there are authorized
8 to be appropriated such sums as may be necessary for
9 each of the fiscal years 2001 through 2005. The author-
10 ization of appropriations established in the preceding sen-
11 tence is in addition to any other authorization of appro-
12 priations that is available for conducting or supporting
13 through the National Institutes of Health research and
14 other activities with respect to autoimmune diseases.”.

15 **TITLE XX—GRADUATE MEDICAL**
16 **EDUCATION PROGRAMS IN**
17 **CHILDREN’S HOSPITALS**

18 **SEC. 2001. EXTENSION OF AUTHORIZATION OF APPROPRIA-**
19 **TIONS.**

20 Section 340E(f) of the Public Health Service Act (42
21 U.S.C. 256e(f)) is amended—

22 (1) in paragraph (1)(A)—

23 (A) in clause (i), by striking “and” at the
24 end;

1 (B) in clause (ii), by striking the period
 2 and inserting “; and”; and

3 (C) by adding at the end the following:

4 “(iii) for each of the fiscal years 2002
 5 through 2005, such sums as may be nec-
 6 essary.”; and

7 (2) in paragraph (2)—

8 (A) in subparagraph (A), by striking
 9 “and” at the end;

10 (B) in subparagraph (B), by striking the
 11 period and inserting “; and”; and

12 (C) by adding at the end the following:

13 “(C) for each of the fiscal years 2002
 14 through 2005, such sums as may be nec-
 15 essary.”.

16 **TITLE XXI—SPECIAL NEEDS OF**
 17 **CHILDREN REGARDING**
 18 **ORGAN TRANSPLANTATION**

19 **SEC. 2101. SHORT TITLE.**

20 This title may be cited as the “Pediatric Organ
 21 Transplantation Improvement Act of 2000”.

1 **SEC. 2102. ORGAN PROCUREMENT AND TRANSPLANTATION**
2 **NETWORK; AMENDMENTS REGARDING NEEDS**
3 **OF CHILDREN.**

4 (a) IN GENERAL.—Section 372(b)(2) of the Public
5 Health Service Act (42 U.S.C. 274(b)(2)) is amended—

6 (1) in subparagraph (J), by striking “and” at
7 the end;

8 (2) in each of subparagraphs (K) and (L), by
9 striking the period and inserting a comma; and

10 (3) by adding at the end the following subpara-
11 graphs:

12 “(M) recognize the differences in health
13 and in organ transplantation issues between
14 children and adults throughout the system and
15 adopt criteria, policies, and procedures that ad-
16 dress the unique health care needs of children,

17 “(N) carry out studies and demonstration
18 projects for the purpose of improving proce-
19 dures for organ donation procurement and allo-
20 cation, including but not limited to projects to
21 examine and attempt to increase transplan-
22 tation among populations with special needs, in-
23 cluding children and individuals who are mem-
24 bers of racial or ethnic minority groups, and
25 among populations with limited access to trans-
26 portation, and

1 “(O) provide that for purposes of this
2 paragraph, the term ‘children’ refers to individ-
3 uals who are under the age of 18.”.

4 (b) STUDY REGARDING IMMUNOSUPPRESSIVE
5 DRUGS.—

6 (1) IN GENERAL.—The Secretary of Health and
7 Human Services (referred to in this subsection as
8 the “Secretary”) shall provide for a study to deter-
9 mine the costs of immunosuppressive drugs that are
10 provided to children pursuant to organ transplants
11 and to determine the extent to which health plans
12 and health insurance cover such costs. The Sec-
13 retary may carry out the study directly or through
14 a grant to the Institute of Medicine (or other public
15 or nonprofit private entity).

16 (2) RECOMMENDATIONS REGARDING CERTAIN
17 ISSUES.—The Secretary shall ensure that, in addi-
18 tion to making determinations under paragraph (1),
19 the study under such paragraph makes recommenda-
20 tions regarding the following issues:

21 (A) The costs of immunosuppressive drugs
22 that are provided to children pursuant to organ
23 transplants and to determine the extent to
24 which health plans, health insurance and gov-
25 ernment programs cover such costs.

1 (B) The extent of denial of organs to be
2 released for transplant by coroners and medical
3 examiners.

4 (C) The special growth and developmental
5 issues that children have pre- and post- organ
6 transplantation.

7 (D) Other issues that are particular to the
8 special health and transplantation needs of chil-
9 dren.

10 (3) REPORT.—The Secretary shall ensure that,
11 not later than December 31, 2000, the study under
12 paragraph (1) is completed and a report describing
13 the findings of the study is submitted to the Con-
14 gress.

15 **TITLE XXII—MISCELLANEOUS**
16 **PROVISIONS**

17 **SEC. 2201. REPORT REGARDING RESEARCH ON RARE DIS-**
18 **EASES IN CHILDREN.**

19 Not later than 180 days after the date of the enact-
20 ment of this Act, the Director of the National Institutes
21 of Health shall submit to the Congress a report on—

22 (1) the activities that, during fiscal year 2000,
23 were conducted and supported by such Institutes
24 with respect to rare diseases in children, including
25 Friedreich's ataxia; and

1 (2) the activities that are planned to be con-
2 ducted and supported by such Institutes with respect
3 to such diseases during the fiscal years 2001
4 through 2005.

5 **TITLE XXIII—EFFECTIVE DATE**

6 **SEC. 2301. EFFECTIVE DATE.**

7 This Act and the amendments made by this Act take
8 effect October 1, 2000, or upon the date of the enactment
9 of this Act, whichever occurs later.

○